Biography

Dr. Stefan Friedrichsdorf is a professor of pediatrics and the medical director of the Center of Pediatric Pain Medicine, Palliative Care and Integrative Medicine program at the Benioff Children’s Hospitals, University of California at San Francisco School of Medicine (UCSF). Dr. Friedrichsdorf has received numerous awards for his work including the 2016 Elizabeth Narcessian Award for Outstanding Educational Achievements in the Field of Pain by the American Pain Society and the 2011 Hastings Center Cunniff-Dixon Physician Award. He is the principal investigator of a National Institutes of Health (NIH) / National Cancer Institute (NCI) multisite study on the creation, implementation and evaluation of the Pediatric Palliative Care Curriculum “Education in Palliative and End-of-Life Care (EPEC)-Pediatrics”, which so far trained 990 clinicians from 66 countries.

Dr. Friedrichsdorf enjoys teaching and in 2008 founded and continues to direct the Annual Pediatric Pain Master Class which is a unique week-long intensive course for interdisciplinary health professionals seeking to achieve a deeper more comprehensive understanding of pain. Dr. Friedrichsdorf has also presented over 750 lectures in 30 countries on topics ranging from pediatric pain medicine, palliative care, and integrative medicine. He has authored and coauthored over 60 peer-reviewed articles and 25 books and book chapters. Dr. Friedrichsdorf is also the current president-elect of the Special Interest Group on Pain in Childhood of the International Association for the Study of Pain (IASP).

Interview Abstract

Dr. Stefan Friedrichsdorf begins the interview by describing his time as medical trainee in Germany and his observations that the medical treatments physicians were giving seriously ill children were often the cause of the distressing pain symptoms children experienced. In his pursuit to find out more about managing pain in children, he found there were no existing resources—no books, no courses, no practices around him. In a chance opportunity, one of his peers was awarded funding to conduct an assessment of pediatric palliative care in Germany, and so Dr. Friedrichsdorf became the manager of that study and began his lifelong mission to eliminate medically caused pain and suffering in children.

Dr. Friedrichsdorf then describes participating in an opportunity sponsored by the Open Society led by George Soros after the fall of East Germany, to participate in several international conferences with other people interested studying pediatric palliative care. This included other like-minded individuals from the United Kingdom, Australia, Albania, the United States, and Canada. Dr. Friedrichsdorf comments on the three different types of healthcare models in the world, how current services and realities were derived from the circumstances created by these healthcare models, and several shocking and egregious situations and practices that he experienced and found to be detrimental to the health of the patient children and their families.

From the friendships he made during the beginning sessions of international pediatric palliative care conferences, Dr. Friedrichsdorf created a successful training collaborative and developed The Educational Palliative and End of life Care (EPEC) pediatrics
training modules and certification resource for practitioners. With this training tool, he expects to continue to see the current and next generations of practitioners be well trained in alleviating pain and distressing symptoms in children.

Dr. Friedrichsdorf concludes the interview by listing his plans to continue to build a future where all practitioners are trained in at least primary palliative care, increase the global access to pediatric palliative and pain care free of economic restrictions, implement a reframing of physician training to stop blindly pushing impractical intensive treatments when a palliative treatment would be more effective at reducing suffering and burden on children, and for the establishment of sustainable interdisciplinary palliative care teams in every children’s hospital.
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<tr>
<td>ACGME</td>
<td>Accreditation Council for Graduate Medical Education</td>
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<tr>
<td>ACT</td>
<td>Association for Children with life-threatening and Terminal conditions</td>
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<tr>
<td>EMLA</td>
<td>Eutectic mixture of lidocaine and prilocaine</td>
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<td>EMT</td>
<td>Emergency medical technician</td>
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<tr>
<td>EPEC</td>
<td>Educational Palliative and End of life Care</td>
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<tr>
<td>HIV/AIDS</td>
<td>Human immunodeficiency virus infection and Acquired Immune Deficiency Syndrome</td>
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<td>IV</td>
<td>Intravenous</td>
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<tr>
<td>NIH</td>
<td>National Institutes of Health</td>
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<tr>
<td>NPO</td>
<td>Nil per os (latin); nothing through the mouth</td>
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<tr>
<td>PICU</td>
<td>Pediatric intensive care unit</td>
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<tr>
<td>PMR</td>
<td>Physical Medicine and Rehabilitation</td>
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<td>USMLE</td>
<td>United States Medical Licensing Examination</td>
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### Interview Roadmap

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Today is August 21st, 2019. I am Bryan Sisk and am in St. Louis, Missouri interviewing Dr. Stefan Friedrichsdorf over the telephone for the Pediatric Palliative Care Oral History Project. Dr. Friedrichsdorf is in Minneapolis, Minnesota. Thank you Dr. Friedrichsdorf for joining me today. To get us started, could you just tell me when your mind turned toward pediatric palliative care as a career focus?

There were many little things which sort of happened over the years. I grew up in Germany and attended medical school in that country. Prior to admission, one was required to do an eight-week practicum in a hospital. So I chose the next children's hospital in the beautiful medieval university town of Lübeck to apply and was accepted on the pediatric oncology unit.

I actually spent eight weeks on the pediatric cancer unit which at that time was a free-standing single house back in the early-90s... Even then, a large number of children could be cured from their malignancies, but of course kids had serious illness and staff and parents were worried they may die. I do remember during the first few weeks one boy who was suffering from advanced cancer, who was abandoned from his parents. His parents were very well off financially and stopped visiting him in his last weeks of life - maybe because they couldn't deal with the fact that their son is dying. At that time it was very unusual situation on the unit because everyone felt sorry for the child and also sorry that his own parents abandoned him and were not coming anymore. So the clinical team went beyond themselves to make sure that the kid had a lot of distraction and lot of people coming in there.

And initially, as the new premed student, I was not supposed to get into this room, but as team got to know me later I was also allowed to provide some care because I was basically working as the assistant nurse. And that was the time when I thought 'we need to do better.' This was good service but was very improvised. At that time there was no designated pediatric palliative care services. So when I started going to medical school, in order to not only to support me financially but also get experience, I continued to work as an assistant nurse in the children's hospital because I was trained as an EMT [Emergency medical technician] as a paramedic. And over the next six years I worked in this children's hospital. Over the time I encountered a large number of children with advanced
cancer and other life limiting diseases. I also noticed clearly that when children were suffering from symptoms such as pain, very often it was actually us clinicians which was causing it. But most of the time most children suffer from pain or distressing symptoms because of the treatment—so either because we are restraining them and stupidly holding them down and putting needles into them for lumbar punctures, bone marrow aspirations, IV [Intravenous] access blood draws without any state of the art modalities to prevent pain; or it would be chemotherapy induced mucositis or other conditions which were causing pain.

So, during medical school, I underwent training outside Germany in Australia, Canada, the United States and the United Kingdom especially. Then in 1998 I was admitted into a five-year pediatric residency program in Germany at one of the largest children's hospitals, the Vest Children’s Hospital in Datteln. And again I looked into 'how can we do this better?'

In most countries at that time, including Germany, there didn’t exist a pediatric pain program or a palliative care program to address unrelieved pain and suffering of hospitalized children. So I tried to read up as much as I could. Fortunately, there was a colleague of mine, Boris Zernikow, who was a year or two ahead of me in his residency training, who really was interested in pain management and palliative care, organizing awareness and training. And so one day I connected with him and inquired about opportunities to learn more on the subject. Coincidently, he just secured a grant from the German Cancer Society to look more into what is actually happening in terms of pediatric palliative care in Germany - and he invited me to become the project manager for this PATE project over the next two years, which basically was at the time geared towards kids with cancer. So one of the components was to reach out to all 79 children's hospitals in Germany who provided cancer care on cancer units and we undertook a survey inquiring what services do they provided in end-of-life care for kids with serious illness, including for parents, for siblings. We published the results in JPSM.

And part of the funding was to promote pediatric palliative care in Germany and as such I was able to visit other countries to observe what program were in existence there. One of the models at the time was in the United Kingdom, a nation which has gone a very different way than, for instance, the United States, as in that their palliative care services earlier on were provided by what they call hospices which is an American term would be like a hospice house or a respite house.
So at the time those British children’s hospices were independent from the National Health Service (NHS) children's hospitals and a house commonly had 10-12 beds providing respite, i.e. recharging batteries for patients and caregivers, but also end-of-life care. So I was able to travel to United Kingdom, meet with the amazing John Overton one of my early mentors who at that time was the president of ACT [Association for Children with life-threatening and Terminal conditions] which was the premier pediatric palliative care organization in the United Kingdom, which is now renamed into Together for Short Lives. And he invited me to Birmingham and I spent times and looking at the three Acorns children's hospices they were running in the area and he introduced me to other people who were running pediatric hospices in London and North England.

I also then visited Dr. Richard Hain, the head of the pediatric palliative care program in Cardiff, Wales and stayed in his house as a guest. We had long conversations about how to start programs and how to take care of children with serious illness. And then I went to Great Ormond Street which is the other big pediatric palliative care inpatient program in the United Kingdom and at the time it was ran by Ann Goldman and met her and her team. So I was majorly influenced by those strong people in the United Kingdom, including John Overton, Richard Hain and Ann Goldman. The other interesting thing that was happening was that Mr. Soros I can’t think of his first name this moment…. He's the—

[Bryan Sisk: The philanthropist?

Stefan Friedrichsdorf: The philanthropist.

[Bryan Sisk: George Soros.

Stefan Friedrichsdorf: Yes, you are correct, thank you Bryan. George Soros originated from Hungary and he at that time in the 1990s—so remember the Soviet Union has just broken down, I grew up in West Germany with communist East Germany still inexistence until 1989, and this old world order was falling apart—so Mr. Soros really wanted to help implement palliative care and especially pediatric palliative care in Eastern European countries.

So what he did, which was quite amazing and quite influential for my career: He offered a course funded by the Open Society which in 1999 took place in Budapest, Hungary and then in 2001 and 2003 respectively in Warsaw, Poland. And the idea of those pediatric palliative care training course was that two people from
each European countries could apply and like he would basically cover their attending cost and they participate in a one-week crush course in pediatric palliative care with many of the leading clinicians in the field who are available on that planet at that time. That was actually meant for people from low to medium income countries from Eastern Europe. So when I heard of that I applied and I was actually accepted both in 2001 and then 2003 then back as a speaker invited to participate … and that was quite literally career changing.

So what happened is that at time was, we were in an outskirt of Warsaw in a hotel with two people from each country. So, at that time, I was spending time for instance with the Albanian Pediatric Palliative Care Service, which at that time was two amazing nurses, who said back home they had one donkey, and a bag of aspirin and no opioids to see children in the mountains. It was fascinating. And I met many colleagues who then became strong collaborators, mentors, and then friends, including Dr. Ann Goldman from London, UK, Richard Hain from Cardiff, UK; I met Leora Kuttner, a psychologist from Vancouver, Chantal Wood from Paris among many others.

We spent a week in that hotel day and night working with each other, so lifelong friendships have happened. And then what happened is that in parallel Dr. John Collins from Sydney, Australia, who spent quite a few years here in the United States for training. He trained at Memorial Sloan-Katering in New York and Boston Children's, and then he went back and actually started an amazing Pediatric Pain and Palliative Care Program in Sydney, Australia at the Children's Hospital at Westmead. He successfully created a new pediatric palliative care fellowship and was looking for candidates so he reached out to his close colleagues seeking for candidates. And Dr. Ann Goldman recommended my name as a contact. So I received an elaborate email, and I am paraphrasing here "Hey, my name is John Collins. I have a fellowship in Sydney, Australia. Are you interested?" At the time I was at the end of my pediatric residency and thought "Wow, what an opportunity."

So with a close deadline I called my girlfriend who I had been dating only for a few months at that time actually at a conference in Austria, she was skiing that very moment and this was the very early days of cell phones so it was like quite an ordeal. And I said, "Sydney?" She said, "Okay," and the rest is history. I interviewed by phone. They offered me position. Ruth, my girlfriend at that time, wife now, and I moved to Sydney, Australia. She's also a
pediatrician. Much smarter than me and also did a training over there and I did the single best piece of training I ever got in my life. I did a pediatric fellowship in pain medicine and palliative care at the Hospital in Westmead under John Collins and his interdisciplinary team.

And then prior to even starting my fellowship, the International Association for the Study of Pain (IASP) Special Interest Group (SIG) of pain and childhood (of which right now incidentally am actually the president elect) held their International Symposium of Pediatric Pain (ISPP) in Sydney. At the time, in the final months of my 5-year pediatric residency, for the first time attended this conference in 2003 in Sydney, Australia. And the details are a little bit murky, but apparently, they include about two bottles of Australian Shiraz from South Australia. I met two medical directors, Dr. Susan Sencer (Pediatric Oncology) and Dr. Tim Culbert (Integrative Medicine) from the Children's Hospital in Minneapolis who shared with me how difficult it had been to try and recruit a pain and palliative care clinician in the United States because the training just doesn't exist.

So mind you I was just about to start my fellowship. I had just come out of my five-year residency and I said "That's great if I know of anyone I'll let you know," not even considering for a second that they were sort of thinking of me. So Children's Minnesota initially with Tim Culbert, the Medical Director of Integrated Medicine and then Susan Sencer, Director of Oncology at that time, then the extraordinairy CMO Dr. Phil Kibort stayed in contact, kept me up to date. There were minor details (sarcasm) such as I was not trained in the United States. But they invited me and I said, "Well, they sent me the airline ticket so I might as well go." And my assumption was, like in Australia there are those underserved areas and nobody wants to go there – so [...] not knowing what to expect and looking up on the map in the mid-west, I assumed that Minneapolis was something like that. Like nobody would go there and they had to get people from the outside. So imagine my surprise to find one of the largest and most advanced Children's Hospital in the United States who was actually offering me a gig… and yes, and it was hard. I had to re-do all the American exams, USMLE [United States Medical Licensing Examination] Step one, then Step two and Step two CS and Step three. And the amount of bureaucracy that was required for it to come to this kind of work was unbelievable. The only thing I didn't have to do was provide a translated footprint of my great-grandmother, but other than that, it's just surprising what I had to put in to become eligible to practice medicine and become a
resident, and finally a citizen, in the United States of America. So the files are still staking up.

And then after finishing my pediatric palliative care and pain fellowship in Sydney, Australia from 2003 to 2005, Ruth and I went back to Germany for a few months to finish up some loose ties. I sat my board exam in Germany and then on—today actually, 14 years ago on August 21st, 2005, we landed highly pregnant in the city of Minneapolis-St. Paul and two days later I sat my Step three exam and a week later I started as the medical director of the Department of Pain Medicine and Palliative Care, which a few years later then became Pain Medicine Palliative Care and Integrative Medicine. And over the last 14 years was lucky enough to meet amazing people and to build one of the largest and most comprehensive programs of its kind in North America and in the world.

Wow, that's quite a story. A couple of things I wanted to go back to. George Soros had a couple of different big philanthropic roles in the development of pediatric palliative care and palliative care, in general, obviously with the Death and Dying in America Project. Thinking about this the course that he offered to low to middle income European countries, what do you think would have happened if that course had never come to be?

It's hard to say because we probably wouldn't have had this talk because without that, I wouldn't have been there. Without that I wouldn't have got to know Ann Goldman who would not have recommended my name to John Collins, and I would not be in this position. I mean the fact that one of the largest most comprehensive program of its kind is in the United States is a direct effect of coincidences led by this. So that's from personal career. How much this has influenced others, it's hard to say. Probably quite immense because at that time it was a very small field.

Half of the faculty were from North America, the other half was from Europe, [including the visionary and charismatic Dr. Tomasz Dangel from Warsaw, whom I later returned to obtain more training in Poland)] (Added by Dr. Friedrichsdorf during review), Great teaching and great networking. So you were in the same room eating breakfast, lunch and dinner and dancing at night in this very intense course with the leading people in the field around. So that was quite amazing, and I think because of networking even now what is it, 2001 to 2019, so 18 years later, it's clearly something which as I said I built friendships and many
professional collaborations. And the gang of Americans who at the time have definitely been part of this, like the Joanne Wolfe, they're now close personal and professional friends and we collaborate on so many issues of pediatric care. So I think that in parallel and together, it has moved the field spectacularly in the right direction.

Bryan Sisk: Thinking back to the late 1980s, early 1990s when you were in that cancer unit for children, what were the biggest challenges in caring for these kids that were suffering?

Stefan Friedrichsdorf: Unfortunately, it hasn't changed a lot in most children's hospitals. So the suffering I have seen in late 80s, early 90s, is what we still see in most of these hospitals around the world. It is basically all researched, and we've published this, shows that all pain in children and suffering in children is under recognized and under treated. Even now as we have this discussion in 2019, the vast majority in children's hospitals in United States and in high-income countries, children suffer needlessly because hospitals are not even implementing very basic modalities of pain treatment and pain prevention.

Something has improved. So in 1985, it was standard of care in the United States to perform open heart surgeries on babies awake. So if you had a infant and your baby would need heart surgery, the infant in 1985 would go to any big center in United States and would be awake. They would open the chest in an awake infant, so that the baby won't scream too much they would give rocuronium, a muscle paralytic to immobilize the child and then maybe some nitrous gas. Open heart surgery is not like these minor surgeries, so it's a large number of babies died just because of the pain. [Particular anxiety-provoking and painful procedures, such as bone-marrow aspiration and lumbar punctures in children with cancer are now routinely done under sedation in high-income countries. But shockingly, this is not true for most children in low-medium income countries yes, where children are still suffering needlessly every day as we speak.] (Added by Dr. Friedrichsdorf during review)

Bryan Sisk: What do you think is the barrier?

Stefan Friedrichsdorf: It's just not a top priority. So if you ask; do you have kids?

Bryan Sisk: I do. I have three.
Stefan Friedrichsdorf: Yeah, so if you ask them and they're in an age where they can answer you and say, "Okay you're going to see the doctor tomorrow," what are they most afraid of?

[00:25:05]
Bryan Sisk: Shots.

Stefan Friedrichsdorf: Shots, needle pokes, right? Because we're holding them down. Kids are super-duper afraid of us, of medical people, because we're holding them down. We put needles into them and it hurts. It hurts a lot and cause a lot of anxiety. And then as soon as the child gets sick then you have to do blood draws and IVs and cannulation… that actually is the number one thing kids don't want to deal with.

Now, preventing needle pain in children is not difficult. In fact, Children’s Minnesota was the first hospital on the planet who has implemented a “Comfort Promise”. We actually promised that every single time a child comes in, we do everything possible to prevent and treat pain. And there are very basic things such as “numb the skin”. So before you put a needle in into a child, we'll numb the skin with 4% lidocaine cream, EMLA [Eutectic mixture of lidocaine and prilocaine] cream, or a J-Tip (needleless application of lidocaine). Never ever, ever, ever hold a child down. There's no situation where it's ever appropriate for elective needle procedures—we're not talking saving lives—to hold down a child and restrain him or her. Yet it's happening left and right because people have been trained like this or it's just they don't want to do this. And you always hear things like, "Oh, Dr. Friedrichsdorf, this sounds good but we just do not have enough staff to implement pain management," but interestingly enough there always seems to be enough staff to restrain children and hold them down.

And with babies you always either offer breastfeeding or sucrose and of course you use age-appropriate distraction.

And with all those four modalities, all of them especially the numbing cream, you find that most children actually do very well, have no pain or very little pain with needle pokes. And those kids who are too anxious, are too afraid because they have been held down too many times or just difficult, for those kids, a nitrous gas program. Here at Children's we have the largest nitrous gas program in the country. Of course this is absolutely amazing because kids come in, they do not have to be “NPO”, meaning they can eat and drink, you give some nitrous gas, you do the procedures, they walk out. So I hear some colleagues saying, "You know, that's just not supported here at my institution," and if you ask their leadership which then are often not visionary people but
people who are just sort of managing things and thinking, 'how do we sort of get this institution running financially.' It often doesn't reach an important enough level because it doesn't sound sexy enough and you hear false claims such as A, “a needle poke doesn't hurt that much”, or “you just have to be quick”, and B, well, that's important but it's not as important as many of the other priorities.

So it's culture change for people to change what they're doing and it's very difficult in the medical system to change things. And then if individuals don't want to do this, they find insane reasons supporting their cognitive bias. For instance, there was one influential person in the hospital in Minnesota came up with the idea that we can't give the numbing cream, as it's recommended in Canada, to families because the toddlers would find the numbing cream in mother's handbag and then they would eat it and then they would die. Despite the fact that there's not a single case in the world literature where this ever happened, I could not convince this person. I then swallowed the cream myself to see what would happen [laughs]. Yeah, it tastes terrible. It numbs your mouth and no child is ever likely going to do this.

Then I wrote to my Canadian colleagues who undertook the research and inquired 'Listen I have this one leadership person here who just doesn't want to do this and one barrier this person is setting up is that he or she doesn't want to hand out the cream to the parents so they can apply the cream on at home prior to vaccination because of perceived danger to children. And the feedback I received from my colleagues was”due to what we heard about numbing cream in American housewives handbag - That's really not the thing we're worried about in American housewives handbags endangering children, right?” So we should acknowledge how many children are killed by guns accidentally or by opioids, other things like that.' So there are people using cognitive bias, if they don't want to do this, they don't want to do.

[00:29:32]

_Bryan Sisk:_ Thinking back outside of pain, how were psychological, social needs, kind of those other aspects of suffering, how are those viewed and addressed, especially when you were starting off in Germany?

_Stefan Friedrichsdorf:_ So in medium to high-income countries there are two different healthcare system. There's United States, and then there's the rest of the planet. So for the rest of the planet, e.g. Canada, Australia, all of Europe, they have some sort of like a reasonable healthcare system where everyone has health insurance which has huge advantage because all kids can get the same care. However, there's
also far less money in the system. So the medical care system in Germany was advanced but decentralized, there were too many hospitals who were too small. For instance, the 300,000 City of Münster in Germany had three separate children's hospitals. That makes no sense to provide state-of-the art medical care. So there were always too few staff then and now, so there were far less resources. Here in the United States there's far more money in the system, which makes it … for better or worse, why it's so expensive to get healthcare, but also means that here the number nurses per patient or number of psychosocial interdisciplinary people added on this is far bigger.

Back then, there were very few services and we have to keep in mind that most children living with life-limiting diseases or dying from life-limiting disease do not have cancer. So the vast majority do not have cancer but that's where all the attention is going to. So then and now in Europe and in America, cancer units usually receive more resources. They get the better publicity. They get more donations. They usually have the extra social worker. The extra therapy dog because it's cancer and that makes people very sad. [There is nothing wrong with this, but we must ensure equal services for children with and without malignancies.] (Added by Dr. Friedrichsdorf during review)

The largest number of children dying in western countries are infants. And that isn't like the NICUs, they really have not invested large and by into a proper palliative care service. The second largest group once you go beyond the NICUs, are children with chromosomal or metabolic progressive degenerative diseases with impairment of the central nervous system. And that is far more, about twice as many of the kids with cancer, but they're usually not as well-known and don't have as good of a lobby.

These kids may for instance have conditions such as mitochondrial diseases, metabolic diseases, or sometimes they are syndromes where only like 10 or 20 such children exist in the world, but they all have in common they're non-verbal, get progressively worse, they have issues with respiratory system and parents are struggling whether not they need to receive a tracheostomy tube and need to be attached to a ventilator. They usually have feeding intolerance and visceral hyperalgesia. They have often need a Gastric-tube or Jejunal-tube, so they need artificial nutrition and hydration. That is a much bigger group of children and they usually bounce forth and back to the PICUs [Pediatric intensive care units] in children's hospitals and then the general units, who also have less far services both in Europe and here in the United States, because they're sort
of become those chronically ill kids. A study in the U.K. did show that about 80% of the children who have been admitted the previous year in British Intensive Care Units were kids with serious advanced illness falling in this group with life-limiting diseases.

[00:34:20]

**Bryan Sisk:** So as you were starting off, and this field was kind of slowly developing around you, and part because of you, what were the biggest challenges you faced as you forged your career?

**Stefan Friedrichsdorf:** Well, there were many. So number one was basically more training—so I came here to a different. I just had finished my fellowship which were probably at that time the best training on the planet, but was still sort of like I felt like, "okay now I really need to learn something." The first thing was basically that I really wanted to learn much more about advanced pain management, because that was the number one most distressing symptom in those children, whether it's cancer or whether it's progressive degenerative conditions. And so I looked left and right, "Is there a course?" There was no course. There was no advanced pediatric pain course, so I invented one with my team. As a result we started the pediatric pain master class in 2008 and since then we've done this mostly annually, which to that day is the single best course on the planet. The reason I can say this with confidence is …it's still the only course of its kind. [*laughs*]

So there is still no competition making this the best course in the world, which is shocking because you would expect a course like this in every country and people from all over the world doing this one-week course in advanced pain management for acute pain, chronic pain, neuropathic pain, visceral pain, total pain, but it's unfortunately not happening yet. So, getting to teach myself and teaching others, because there wasn't really a lot of structures at that time, was a big thing. The curricula were great but many curricula for pediatric palliative care at that time really concentrated on psycho-social-spiritual, and communication areas were very, very short on advanced pain and symptom management.

So I was lucky to basically submit, with lots of help from amazing collaborators, an NIH [National Institutes of Health] grant and in 2010 it was granted over $1,600,000 from the National Cancer Institute in the National Institute of Health to build a pediatric palliative care curriculum and dissemination model. So we were basically basing on an excellent adult program and then totally
rewrote a pediatric version of EPEC [Educational Palliative and End of life Care]-Pediatrics, which now has become the most comprehensive pediatric palliative care curriculum worldwide, which can be done online and in-person and will really teach how to teach pediatric palliative care topics so that you can change behavior among your audience. So we just published the results of that in JPSM in 20219 and so far we have trained nearly 900 clinicians from 58 countries on all six continents. We were not in Antarctica yet but working on that... It seems like each person taking this course and becomes a “Trainer” seems to teach roughly another 70-110 people. So we're still trying to find out the number but it's at least more than 39,000 people have been trained so far by those 600 initial Trainers we trained, so that is a pretty good thing.

So looking back, teaching how to teach, getting to get the information out and raising understanding, was of course one major task. And the other thing also is when you become a leader, there's no training how to be a leader. How do you run a team? How do you get the feedback? It takes a long time and one has to be very deliberate about this and the importance of team building and learning for myself what I'm good at and what I'm not good at. Thank god for leadership coaching!

[B00:39:01]

**Bryan Sisk:**

So overall, what do you think was the real spark that started the development of pediatric palliative care as a philosophy and eventually a specialty?

**Stefan Friedrichsdorf:** I think there were several things. First, people who choose to go into pediatric medicine overwhelmingly are good people. So it's not an area where you make money compared to other medical specialties. It's often special kind of people who want to do this. And of course there are silly people like everywhere in every field, but by far most people get up in the morning because they want to help children and the families. Watching suffering, watching pain, anyone who's sensible wants to avoid this and unfortunately, most children's hospitals do not make it easy to eradicate pain to eradicate their suffering. So there's a genuine interest among every staff member to decrease suffering, to eradicate suffering, to decrease pain, to eradicate pain.

The media influences the perception of the public that children don’t die anymore. Now the general public watches television and people have strange diseases and then heart stops and then they receive CPR and then five minutes later they walk out of the room completely healthy, that of course is not true. People just feel that
nowadays kids don't die anymore and yet, about 50,000 children die every year in the United States and so that's a big number.

If you just put this into context; if you just put children with life-limiting diseases in America into a Boeing 747, which has 429 seats, that would mean every seven days a Boeing 747 crashes in the United States, just full of children. And you are very unlikely to choose an airline which loses Boeing 747 every seven days. That airline however is called the American healthcare system because those airplanes, we're not even talking about siblings, we're not talking about parents, we're not talking about grandparents or classmates, so a much larger number of people are affected. Unfortunately, the vast majority, more than 90% of those kids die in pain without adequate pain relief, they die with distressing symptoms such as nausea, and they die without ever having seen anyone who's even vaguely trained in pediatric palliative care in 2019.

So those individuals, those early figures who've done this here in the US, including Chris Feudtner in Philadelphia, Joanne Wolfe in Boston, Jody Chrastek and Stacy Remke in Minneapolis, Sarah Friebert in Akron implemented clinical programs and standards here in the country. And then in parallel in Europe, Ann Goldman in UK, Tomasz Dangel in Poland, Anna Gorchakova in Belarus. So these early 1980s, 1990 pioneers who have done this, most of them really have formed something in us...like, "Wow I want to be like that."

The single most important thing which happened to really make this a big movement in the United States was that the American Board of Pediatrics participated to have an ACGME-accredited fellowship for certification in hospice and palliative medicine. Then suddenly pediatric palliative care became “real”. There was a clinical pathway to a career with training and an exam. So for reasons, which are completely utterly non-understandable absolutely insane, you cannot be a pain doctor when you're a pediatrician in the US. As a pain specialist, there's no ACGME training because the American Board of Pediatrics is not endorsing that yet. Other disciplines participate in the pain board exam, only the American Board of Pediatrics lack dangerously behind. So if you're a psychiatrist, a PMR [Physical Medicine and Rehabilitation] doctor, a neurologist, you can undertake a fellowship and sit for the pain board. But as a pediatrician you can't... and similarly to the palliative care pathway if we were to have this, pain management for children in our country would
become much, much, much better because people then would do a fellowship in palliative care and a fellowship in pain.

So that was a long answer, in short: number one, the undercurrent of good people at children's hospitals. Number two, individuals who really formed the field, and number three is basically the decision by to have the hospice and palliative care certification and that there's a career towards that.

Bryan Sisk: So following up on that, pain medicine and palliative care have similar overlapping goals, how have you seen those different specialties interact over time? Have they strongly interacted or have they kind of been in parallel way?

Stefan Friedrichsdorf: Well, the problem is that there's the misconception that pediatric pain medicine in United States is sort of exclusively provided by anesthesia and that of course is incorrect. Do not get me wrong pediatric anesthesiologists are critically important in providing pain treatment and there are especially those who have done a pediatric pain fellowship are outstanding in a large number of pain medicine aspects. So we have one of the largest pain and palliative care programs and when last week we had—it was a very busy week. We had more than 40 patients on our daily inpatient census. Not a single one of them actually required a new procedure such as epidural or a regional block or anything like this. So meaning there were lots of neuropathic pain, visceral pain, chronic pain, on top of acute post-operative pain. So pain medicine needs to be seen as interdisciplinary and this needs to be also led by pediatricians together in conjunction with nurses, nurse practitioners, psychologist, physical therapist and so on.

So the concept of what is pediatric palliative care actually entails is very different all over the United States. According to Chris Feudtner's publication a few years ago, it appears that around about 50% up to 70% of the 220 American Children's Hospitals do indeed have a pediatric palliative care program. But if you look closer most of them are severely understaffed. They only provide a Monday to Friday service, not on weekends, not after hours and there are very, very few people who are doing this. So what does it actually mean? For us here in Minneapolis and many big programs are very similar, if we got the consult, we can help with aggressively addressing distracting symptoms such as pain, nausea, constipation, because we're trained to do this.

However, in parallel there have been some programs who rather feel like palliative care is exclusively of the psychosocial-spiritual
aspect of care and decision making and finding out what the parents or what the kids are hoping for and support to make this happen. And those programs leave pain and symptom management to a completely different team. Some programs are joined pain and palliative care services, like ours, others are separate. So we don't know which one is better. As the saying goes “If you've seen one pediatric palliative care program, you've seen one pediatric palliative program”. Certainly I'm a big proponent, and that's my niche, of saying if you're a clinician providing pediatric palliative care, I expect you to really be good in pain treatment and management of distressing symptoms of nausea, vomiting, of constipation, of diarrhea and you need to know your stuff well. And I think our field is going there. EPEC-Pediatrics, our training curriculum as a result has dedicated half the 24 modules to treatment of pain and distressing symptoms. It's a much bigger emphasis than any other curriculum. But you will ask some people in the PPC field who really feel very strongly that that's not their job. They argue their job is to discuss with families and leave the pain and symptom management to others; the oncologist, the cardiologist, the intensivist, or to a separate pain service. And there are very, very successful programs where you have a separate pain service and a separate palliative care service. Boston Children's would be a good case in point, and your very successful programs were this is one, Cincinnati or my program would be one of those, UCSF [University of California at San Francisco] would be another example. But you also have a large number of examples that really are not working well, where the pain service is [coughing]—sorry I've aspirated, I did not have an emotional breakdown. I'll just have some tea.

Yes, so unfortunately a large number of children's hospitals who do have a palliative care service are completely understaffed. And then some have a pediatric pain service which is completely run by anesthesiology, where the anesthesiologists are not doing full time pain service, [but are mostly in the operating room. In order to become a pediatric pain specialist, or any other field in medicine, one must spend the majority of one’s time doing it. It may be much more difficult providing excellent pain treatment, if you are only doing it for a limited time of the year.] (Added by Dr. Friedrichsdorf during review) So how services are provided depends on your culture and every hospital is different.

So I would never suggest, "you have to do this," because each culture at an institution is very different, but every single children’s hospital absolutely needs a dedicated advanced pain service, absolutely need a dedicated advanced palliative care
service, and either it's one program or it's like a program which works really closely to the others. Just doing it as a hobby—if you're an anesthesiologist who walks out of the operating room and are just doing it once a week or once a month, there for one day before and after the operating room, that's not a dedicated pain service. Or palliative care who do this for like a 0.2 FTE on top of their main clinician at the hospital intensivist, cardiologist, or oncologist that's not a designated palliative care program. That's just like the first big step into the right direction.

What do you have been the biggest changes that you've seen over your career and the care that we provide to these kids?

I think that now since it has become a proper career, it has become clear to children's hospital leaderships that a proper children's hospital must have a pediatric palliative care program. And when you go to that step, then it's clear that the expectations are interdisciplinary program. So, it's not really any more the question "should we get the program," which there were very few at the beginning of my career, to "how elaborate should our program be." Yeah, so not one of the top 10, or top 20, or top 50 children's hospitals do not have a pediatric palliative program. However, many of them actually really have not implemented the right resources yet and are striving to do so because they see competing requirements and unfortunately often the leadership has not seen the light yet. So it has become mainstream, I think that's one thing. The other thing is basically the field has moved from palliative care to sort of providing the psychosocial-spiritual aspect only, to the vast majority realizing that advanced pain and symptom management is integral to part of pediatric palliative care to ensure that children live as long as possible as well as possible.

And where do you think the field needs most to grow?

If you look at the number of affected children, there will never be enough pediatric palliative care specialists to see every single child with a serious illness. So we need to increase the number of professionals able to provide specialist PPC. The most important thing is to have sustainable pediatric palliative care program at every single children's hospital. Most of them right now are not sustainable. It's like one nurse practitioner, one doctor and if they're on vacation, there's like no plan B. There's no-one able answer the call or so it's not a sustainable model. People burn out and they just can't do it, and you have to say no to many of the consultants. So the single most important thing is for children's
hospitals to provide sufficient funding to have interdisciplinary teams who can really see the number of patients there, and it's more than one person so that people can go on teaching, on vacation and stuff like this.

Secondly, I think it's very important for us to teach primary palliative care. The adult palliative care model is quite interesting. The mortality rate is 100% so if you work in adult medicine, all your patients are actually going to die 100%. So there are lots and lots of adult palliative care service, hospice services around there. And many of them are not very comfortable in taking care of children yet. And here in Minneapolis, Minnesota, we're covering an area the size of Germany and France. We see children from North Dakota, South Dakota, from Iowa, from half of Wisconsin and Minnesota, that's a big area and although most of them live in the metro area, but what you do out in small rural areas? So we need to work with pediatricians or family physicians or adult hospice agencies and teach them primary pediatric palliative care. Sort of like what is the basic PPC stuff that all of us can do as just a part of good medicine. And EPEC-Pediatrics is like the step in the right direction of training people sort of those basic things, but we have to do much better because even now 2019 most medical trainees in pediatric specialties or adult medicine have really no pain training or training of distressing symptoms such as nausea, vomiting, constipation. I mean advanced pain symptom management is just not taught in fellowship either, so increasing the knowledge among every clinician, raising the bar, in pediatrics for that matter, is key.

Okay, just one last question. I would love for you to just dream a loud if the budget, the politics, and all the other things we talked about, if none of those were obstacles what would you ideally want care for these children to look like another 10 years?

So what we want is for children to live as long as possible, as well as possible. What we would like is that most of those children can be home most of the time. With few exceptions, none of those kids, none of those families want to be in the hospital. So step one is to have that every single children's hospital has an advanced pain and palliative care program. Whether that's a joint program or two separate ones is yet to be seen, but something so that people are trained and at 3 o'clock in the morning, somebody can answer the phone. So we need to get enough people trained in these skills.

Step two, is basically ensure that those kids stay at home as long as possible, as well as possible. So working together with home care
services who can go out at 3 o'clock morning and can help with the clogged J-tube so that those kids do not have to go the emergency room and are fine with addressing distressing symptoms and treat a pain crisis.

And lastly, that the truth of course in our country is that a large number of children live in poverty, disenfranchised, suffering from systemic racism and they just don't have a stable home. They may live in shelters or they have no stable home or environments in their families. So they need a different place. My hope is that in collaboration with the existing tertiary centers who already provide the palliative care, not in competition to them, which unfortunately sometimes happens, we develop what the U.K. or Australia has, those free standing children's hospitals, respite houses, who then in close collaboration with the centers can basically provide home from home, so that those kids who for one reason or the other, can't be at home because or they just need some respite—that this can be delivered so that we really have those three level of cares that families and their kids can choose.

And lastly, we should have better training and stop offering stupid things. So the problem in American medicine of course is that in order to have family-centered care, we sometimes go overboard in family discussion, “well your child has meningitis and needs an antibiotic. I can't tell you which one. Here's the data. You have to choose between Cefuroxime or Ceftriaxone or Vancomycin, your choice.” We don't do that. We basically say "your kid has meningitis, needs this antibiotic," done. This is our recommendation. Yet whenever children have serious illness, [we shy away from recommendations and may offer interventions which make no sense in the false believe we have to offer something to maintain hope. Using dark humor.] (Added by Dr. Friedrichsdorf during review) its basically, "Oh well I can't tell you. We either have to keep this child on ECMO, (extracorporeal membrane oxygenation) or have to do a tracheostomy or we do the experimental brain transplant in Baltimore. You have to choose, I can't tell you." Suddenly we feel that we don’t want to give a recommendation

The job of a parent is to have no stone unturned for your child. You have three kids. I have three kids. We do everything in our power to make sure that our kids live as long as possible, as well as possible. If somebody says there is “something we can do”, then people are going to grab at this. I have overheard a conversation where a baby was born 23 weeks prematurely with significant necrotizing enterocolitis who has no colon left. A clinician from a
specialis team came in and said to the parents, "Yeah well we just have to get them a bowel transplant." Despite the fact that there's not a single child to my knowledge younger than one year who has ever survived a bowel transplant, this is not a reasonable thing to say families. But this particular family then of course clung to this hope. For many, many, many months, the plan was to sort of try to make this child grow enough and old enough that it could undergo a transplant, unfortunately she eventually died.

So we have to also teach our colleagues who feel like offering something is sort of like, "if we don't do this and we destroy hope," to really stop offering stupid things and really start making recommendations which are in the best interest of the family. And you can say, "I like this. This is my recommendation. You may choose differently, and you might find something out there, but here's why a “brain transplant in Baltimore” is not in the best interest of your child."

[01:01:19]
Bryan Sisk: Those are all the questions I had. Is there any part of history you think I really glossed over or I should dig deeper into?

Stefan Friedrichsdorf: This is North American history or World history?

[01:01:30]
Bryan Sisk: I'm trying to get primarily North America and U.K., but getting a sense of the world as well.

Stefan Friedrichsdorf: So I think the interesting piece is this has been something parallel. Even now until very recently, there's been sort of very little European and American collaboration because the models are so, so different. In United Kingdom, the model really has been children's hospitals were like—I'm over simplifying—"Children's hospitals, a terrible place to die," so some lovely nurses basically starting with Dame Cicely Saunders built this hospice house, a place to die in dignity and there's lot of philanthropy who started to hit the ground. If you go to United Kingdom now, there are nearly 50 children's hospices all over the country.

However, there are very few children's hospitals in the UK that actually has a palliative care service, so inpatient pediatric palliative care is actually very poor outside like a few centers. It's basically like how it was 20 years ago here, but the system is very different because the base of palliative care is sort of those pediatric hospice houses, where here it's the other way round.

We in America and Canada felt that—and I feel rightly so, that the discipline needs to come out of the children's hospital as a
specialty and then those tertiary centers have to go out in the community. So and this is why there isn't a lot of collaboration which is sort of interesting. Australia and New Zealand has sort of a middle ground. They're more American but also being ex-British colonies have sort of more hospices. But many European countries really have not, even now in 2019, have not invested in either. So like Spain, actually Greece has some centers that are doing this, but most children still to this day do not have access to advanced pain and palliative care in most European countries, whether they're high income or low to medium income. And many of the very early people actually were like in low – medium income countries including Anna Gorchakova in Belarus and Tomasz Dangel in Warsaw, Poland. So they started the biggest home hospice program in their respective countries. Then I have a home hospice which is like a home care program or Anna Gorchakova in Belarus who has like the largest home hospice program in Europe. Or Joan Marston in South Africa; she and her team took care of kids with HIV/AIDS [Human immunodeficiency virus infection and Acquired Immune Deficiency Syndrome] every day. So if I tell you that we're overwhelmed by like 40 patients per day on a really, really busy day, then she actually has 700 patients per day. So the numbers—we're so often America-centric. Most kids do not live in America. Most kids do not have cancer. And so if you can make sure that you cover this in your history and sort of making it less U.S.-centric and that would be great.

[01:04:58]

**Bryan Sisk:** Absolutely, very helpful. Any last thoughts before we end?

**Stefan Friedrichsdorf:** No, good luck. Thanks for doing this. Make us proud.

*[End of Audio]*