Joan Marston Oral History.

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Biography
Ms. Joan Marston received Bachelor of Social Science and Nursing from University of KwaZulu-Natal in South Africa. She began her career in children’s palliative care at the height of the HIV/AIDS crisis in South Africa, which largely ignored the profound impacts on children. Ms. Marston founded one of the earliest and now the longest existing children’s hospice in South Africa, known as the Sunflower Children’s Hospice, as a response to the exponential need at the height of the HIV/AIDS pandemic. She later assisted in developing and implementing multiple palliative care services for children throughout South Africa as the Paediatric Palliative Care Manager for the Hospice Palliative Care Association of South Africa. Ms. Marston co-founded and then became the first Chair and then Chief Executive Officer of the International Children's Palliative Care Network and remains an international and global ambassador and advocate for children who needed palliative care services. She has aided many low-resource countries with their own child palliative care needs. Ms. Marston’s currently focusing on the Palliative Care in Humanitarian Aid Situations and Emergencies (PalCHASE) organization that she has co-founded which aims to analyze and deliver palliative care needs during catastrophic events. She plans to write a book on her experiences in the child palliative care field.

Interview Abstract
Ms. Marston introduces her career beginnings as a response to the HIV/AIDS crisis in South Africa and describes some of the memorable experiences with youth she cared for. She explains her role in the initial implementation of pediatric palliative day care and home care as well as some of the challenges around growing provider, political, and community education in South Africa. Ms. Marston then talks about her international experiences meeting other in pioneers in the pediatric palliative care field. She touches on her work in developing hospice programs as well as some of the global challenges she’s experienced while establishing palliative care programs. Ms. Marston then goes on to itemize some of the challenges she’s faced in her career and successful methods to counteract those barriers. She concludes with her vision of child palliative care to be integrated into universal health coverage and “accessible to every child’s needs.”

Glossary of Acronyms

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<tr>
<td>ACT</td>
<td>Association for Children's Palliative Care</td>
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<tr>
<td>AZT</td>
<td>Azidothymidine, an antiretroviral</td>
</tr>
<tr>
<td>EAPC</td>
<td>European Association for Palliative Care</td>
</tr>
<tr>
<td>GPs</td>
<td>General Practitioner</td>
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<tr>
<td>HIV / AIDS</td>
<td>Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome</td>
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<td>NHPCA</td>
<td>Hospice Palliative Care Association</td>
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<td>Acronym</td>
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<tr>
<td>PalCHASE</td>
<td>Palliative Care in Humanitarian Aid Situations and Emergencies</td>
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<td>UN</td>
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<td>UNICEF</td>
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Today is May 7th, 2019. I am Bryan Sisk and I'm in St. Louis, Missouri interviewing Joan Marston over the telephone for the pediatric palliative care oral history project. Ms. Marston is in Bloemfontein, South Africa. Thank you, Ms. Marston, for joining me today. To get us started, could you tell me what initially turned your mind toward children's palliative care as a career focus?

Yes. Well, I'm a nurse by profession, and 30 years ago I started working with hospice here in Bloemfontein just as a volunteer and then as a hospice nurse and hospice manager. It was the time when HIV/AIDS [Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome] was just becoming a real problem. As the problem grew and developed, we started seeing more and more children. At that time, we didn't have antiretrovirals in South Africa, so the children were dying, and most of them were dying before they turned four, and so while—at that time, I was managing a general hospice home care program.

I decided that because children have special needs and they are different in the approach that we need to use, and because those children at the time, many of them—of course, their parents were either dying or had died. Home was not always the best place for them to be. I actually approached our head of health and said to him, "Look, we're seeing all of these children, some we can care for at home, but the hospitals don't want them. They're overrun with this. We need a place."

Fortunately, he was a pediatrician, and he understood immediately what I was talking about. He said, "Right, let's look for a place." We found a little house in the grounds of the district hospital, which we opened the Sunflower House in 1998, so 21 years ago. It was linked to a very big outreach program because we had—most of our children were, of course, in the community. We developed a children's palliative day care center. They had six at one stage in quite far-flung places, just in—it really was in response to HIV and AIDS that I first became involved.

I learned from the children. There was no real pediatric palliative care in Africa at the time, although the hospices were caring for children. We actually had to make up our own training courses. We had to read. When we were fortunate enough to travel, we would go and visit a children's hospice in the U.K. [United Kingdom].
It really was HIV and AIDS that brought me into pediatric palliative care. Of course, that became my passion because I'd always loved working with children. We'd always had children in our ordinary hospice program, but it really was this exponential growth of sick children that led to my involvement with pediatric palliative care.

Bryan Sisk: This is a common thread I've heard from several people is how hospice, from the beginning, has had children in it, but children hadn't become the focus of palliative and hospice care until later. What was lacking for these children who were cared for in the adult hospices?

Joan Marston: I think because the numbers of children were very small compared to the number of adults. If I think of my program before this tidal wave of AIDS hit us, we'd have one or perhaps two children. There'd been widely different ages. They got really good care, but they would have to come to the adult-focused day care. Simply, the staff were not trained in any depth in dealing with children. I think it was at least having an environment that was conducive to the children.

Secondly, there was a lack of more in-depth training. At the time, there wasn't a lot of training available anywhere. It was not really having a program that one could call child-focused, or having individuals in the program whose focus was children. That's what we did when we started our children's program which we originally called St. Nicholas Children's Hospice. It's now Sunflower Children's Hospice, but we then put aside staff whose focus was entirely on the children. I think it was a growth and development, but I think it was the lack of numbers in the beginning. They were like an add-on to your program rather than an integral part of the program.

Bryan Sisk: Was there any particular moment or experience that really turned your mind on to this, or was it something that came gradually over time?

Joan Marston: It had started gradually. Then one day, we had—we used to have a regular day care at our hospice house. Two children particularly came into the day care on one specific day. One was a little girl called Refilwe, who looked like a newborn even though she was six months old. I still remember the day. We carried her around the whole day, and she smiled. Her eyes used to focus on the light on the leaves in the trees. We were in the grounds of the cathedral at that time.
In fact, you could see the bishop who lived there. Then she went back to the children's home, and she actually died that night. That had a profound impact on me because I thought she should've died in a place where she continued to have this absolute focused attention. Then on the same day, a little boy called Thabo Matwabeng joined that program, and he was four. He'd been abandoned at birth. They called him Thabo which means "gift" and Mafikeng, which is the place where he was found.

He'd been brought up in the children's home and only recently diagnosed with AIDS. He was a lovely, cheeky, smiley, happy little boy. He really taught us about what he needed. He wanted to be surrounded by people who loved him like a family. He wanted to play games. He wanted to be outside in the garden. In the children's home with huge numbers, it just was not the ideal place for him.

While we've learned from every child who's come into the program, it was really Refilwe and Tabo who, on one particular afternoon, I just thought, "This is it. We have got to do something." I phoned and made that appointment with the head of health to say we just have to do something specifically for the children. That would've been at the end of 2004, beginning of 2005, because we opened our hospice in June 2005—not 2005, 1998, sorry, 1998.

Bryan Sisk:
It sounds like the confluence of seeing this need plus this overwhelming HIV pandemic really sparked this. Has the focus been on HIV primarily, or has the makeup of the diseases these children have changed over time?

Joan Marston:
It's changed over time. In the beginning, it really was primarily HIV, although we always admitted children with any kind of life-limiting condition. We had our children with trisomies, genetic problems, degenerative conditions, cystic fibrosis. We always had those children as well, but the overwhelming numbers were HIV. Of course, from the time that we managed to get antiretrovirals as a government service and remembering that nearly all our kids came from very, very poor, deprived areas where the families could not afford to buy even a bottle of paracetamol syrup, let alone antiretrovirals.

That really changed the face of HIV in that we were able to put our kids onto antiretrovirals, and they responded. Most of them responded beautifully and quickly. I'd say in the last five, six years, the balance has changed. Now more of the children in that
particular program are children with conditions other than HIV. We'll only get a child with AIDS if they're defaulted on treatment and become really sick, and if there are social problems as well that contributed to that. Because, of course, living in a low-resource country and working with children who live mostly in the townships and shacks there are lots of social problems. Yes. The picture has changed with HIV over those years.

[00:09:35]

Bryan Sisk: When you were starting out, was there a community of similar minds that you were able to tap into, or did you feel like you were on your own?

Joan Marston: At the time, it felt I little on my own. Because, yes, the hospices were seeing children, and there were others hospices in Johannesburg—two programs in Johannesburg started a specific program for children. It wasn't totally on our own, but we didn't have the easy access to the internet and Skype and things like that in those days. Being part of the bigger hospice community in South Africa helped as well, but it was only later on—and that's really skipping forward when we started moving towards the International Children's Palliative Care Network—that we really were able to link people together.

That's really going ahead in time because I had a gap where I worked for the national Hospice Palliative Care Association. I set up their pediatric palliative care program as well. At that particular time, in the 1990s, you felt rather alone because we were developing our own training programs. When I think of it now, what we were teaching was so basic. Because we were quite unique, countries who had HIV policies were coming to us and saying, "Please teach us a little bit about how to look after these children, teach our workers how to look after the children."

There were always others that one could connect to. Of course, the pediatric departments and—although they didn't in the beginning think they needed a children's hospice until they saw the work that we did. Then they supported us fully. It was fairly isolated in the beginning.

[00:11:37]

Bryan Sisk: Was the foothold and development of children's palliative care primarily the outpatient hospice, or was there also a foothold within the children's hospitals?

Joan Marston: What tended to happen in the hospitals is that—because in those days, the sheer numbers of people infected were huge, that they would take the children to treatment, so rehydration, treatment for
the severe infections, but they'd want to get them out again as quickly as possible. The main program throughout Africa was the home care program. Our children's hospice, Sunflower House, was one of the very few units—it still is one of the very few pediatric palliative care units in South Africa. But at that time, the main program was home-based care. We had over 1,000 children on the program at one stage at the height of the epidemic.

[00:12:40]

Bryan Sisk: Around this time, around the mid- to late-90s, in the States and in the U.K. there was also this developing, growing foothold of children's palliative care. Was that something that you were—at the time, or was there a dividing line between South Africa and the UK and the U.S.?

Joan Marston: Mm-hmm.

Bryan Sisk: - aware of at the time, or was there a dividing line between South Africa and the UK and the U.S.?

Joan Marston: We were aware of it, but as I said, we didn't have that easy access to information that we have now. Certainly over the years, with the U.K., there was more of a connection. A little bit later on, then I took on the job as the advocacy officer for the National Association. Then I really started to develop the stronger links with other organizations in different parts of the world.

In the beginning, I knew of Sister Frances Dominica. I'd always had a huge admiration for the work that she did, but there weren't many other names that were familiar to me at that time. There weren't many textbooks available in—well, there wasn't any palliative text working from a pediatric basis. We developed our training program.

[00:13:59]

Bryan Sisk: You had mentioned that you learned from the children. Were there any other places—

Joan Marston: Absolutely.

Bryan Sisk: - where you went for information or went for insights?

Joan Marston: Yes. Well, certainly working with the pediatricians and working in the pediatric units in the hospital, learning the basic pediatric nursing care from them. Again remember, this was the 1990s. The hospices didn't have very much money. We couldn't really travel very extensively.

I had made contact with Barbara Gelb in the U.K. At that time, she was the head of what became Children's Hospice U.K. I think it
was the Association of Children's Hospices then, because she was a South African. I cannot quite remember how it is I came into contact, but we did. We used to keep contact.

I'd learn from Barbara, but it was only really when I became the national advocacy officer in 2002 that I started getting to meet people, especially in Europe. Not so much the American connection, although Stefan Friedrichsdorf was in Germany at that time and he was my link to, really the European group. Then later on as I got to know more people, I got to know the group in America and, of course, the greats in Europe like Anna Gorchakova and Tomasz Dangel.

[00:15:45]

**Bryan Sisk:** When you were first starting out, you talked about just the sheer numbers of children that needed to be cared for. How else was care lacking at that time for these children?

**Joan Marston:** It was more social issues, basic things. The kid that was—these kids were living in abject poverty. They were living in shacks. They didn't have basics like food, things that was many of the things that we'd say to patients: eat a healthy diet, live in a hygienic environment, take time to rest. All of those kinds of things that we were saying to some of our patients—before these kids could have that kind of thing, you'd have to take food and clothing and things to give them some kind of a social ground. I would say it was more the things socially that were lacking and, of course, the antiretrovirals—that really big thing. If we'd had antiretrovirals, we wouldn't have had this huge need that we had at the time. Honestly, really, we didn't.

**Bryan Sisk:** Then who was—

**Joan Marston:** There was the other big lacking, of course, was the lack of political will.

[00:17:09]

**Bryan Sisk:** Why do you think that was?

**Joan Marston:** Well, you know, we had a president who didn't believe that HIV caused AIDS. We had a minister of health that he appointed who believed that if gave these kids beetroots and olive oil and lemon juice, that actually that would control the HIV. It really and truly was we had a president and a minister of health, the two highest authorities in health in the country, who were turning away money that was offered from the U.S., USAID [The United States Agency for International Development]. It was a horrific time because it was just so frustrating that we knew that so many of these deaths
could've been prevented if only we had had access. We had the odd tension, that simply because they had the money, we could give AZT [Azidothymidine], which was all that was available in those early days. They could at least afford to get it, but like I said, these communities lived in abject poverty. There was no way. They couldn't even provide enough food for their children, let alone antiretroviral therapy. There were social conditions, political will—it was a combination of really bad factors that came together. I don't know if you know the story, but it actually took the HIV advocates to take our government to the constitutional court to get antiretrovirals into the country.

*Bryan Sisk:* Wow. Wow. That was around here?

*Joan Marston:* The constitutional court, which was the highest court. That must have been going on from about 2002.

*Bryan Sisk:* Wow. You were pushing to care for these children that the government didn't even believe needed anything more than olive oil, beet juice and supplements.

*Joan Marston:* No. The sad thing, it wasn't even—most of the government employees knew that HIV caused AIDS and knew that just by changing those diets to these silly things—I mean, who could afford olive oil when you live in a shack? Those weren't going to work, but it was because we had that president and this minister of health who were totally fixated on the fact that HIV doesn't cause AIDS, and we had these AIDS denialists as well. We had these numbers, these huge numbers.

You know looking back, we'd sometimes have two or three deaths a day. It's so frustrating because you knew that there was something that could be done for these children. Even just giving them good diets, which of course we did when they were in the House—it wasn't going to help them. It wasn't going to save them. We really went through this very dark time. That was political will at the highest level, and it was only the activists—the Treatment Action Campaign took the government to the constitutional court.

It was around the issue of mother-to-child transmission. They said, "According to international human rights, every child has the right to life. By not giving antiretrovirals to the mother, you're denying that right." That constitutional court upheld it, and the interesting thing to happen was the constitutional court said antiretrovirals must be provided. The provincial governments had quietly been getting everything into place so that as soon as they got the drugs
they could be issued. It was simply having these two people in such powerful positions that held us up.

[00:21:25]

**Bryan Sisk:** In terms of the children that couldn't have—didn't have access to the hospice, because you only had initially one and then only a handful of hospices—so were there other options for these kids that either couldn't travel or didn't fit in the hospice because of space issues?

**Joan Marston:** Well, as I say, the hospices all had mainly home care programs. So very few hospices, even now, have got units where you can admit either a child or an adult for full-time care. Home care, and of course we had the development of the community health workers, and they were able—I was plotting a group to develop the training course for the community health workers. They managed to get some funding through one of the big pharmaceutical companies and to actually employ within our province. We worked with the government on this.

That's why I say it wasn't a lack of the will of people within government, it was the two top people who blocked everything. We also had this large cadre of community care workers who were ordinary people that we just trained them the basics of home care. If they were lucky enough to get into home care, then of course care within the community. We've always had a good network of primary health care clinics within the community, so they could go there and get the basics. For the majority of children, even now, there's a limit to access to palliative care.

[00:23:16]

**Bryan Sisk:** You had talked about some different committees that you had joined and helped to start, like I think you said the HPCA and then the ICPCN [International Children's Palliative Care Network]. Could you tell me a little more about how those started and how you got involved in those?

**Joan Marston:** Yes. With HPCA, the Hospice Palliative Care Association—so I'm just gonna have a drink of some water.

**Bryan Sisk:** Okay.

**Joan Marston:** I'd been invited early on in my involvement with hospice to join the national patient care training subcommittee, which we all did as volunteers from our hospice having done some research. Then the national association got funding for an advocacy officer position. I'd been quite active in advocacy around HIV with both, with provincial government and at the national meetings as well.
Anyway, to cut a long story short, they eventually offered me the job. It was very hard for leaving my actual hands-on care for various reasons. I thought, well, maybe this was something I should take on because I feel so passionate about palliative care, and especially for children. It was actually in that capacity I travelled to the UK. I had made contact with the EAPC, and they put me in touch with Stefan Friedrichsdorf. I said, "Well, I'm coming over to the UK. Is there anyone that you think I should meet?" He told me about Richard Hain, about Ann Goldman.

Then he said, "But you know there's a workshop in Warsaw. Tomasz Dangel from the Warsaw Hospice for Children. It's his second workshop. People come from all around the world who are interested in pediatric palliative care." He said, "If you can get there, I can get you into the workshop," which was wonderful. That was really the way I got into the pediatric palliative care community was through my special interest into the international community was through originally my contacts with Stephen.

Then it was in 2003 that I went to a workshop by Tomasz Dangel. Of course, he's one of the greats of the early movement of children's palliative care. There, I came into contact with people, as I said, face-to-face with people like Ann Goldman, Richard Hain, Sue Fowler-Kerry and a number of other people who were doing pediatric palliative care in different parts of the world. A little bit later, I met up with Barbara Gelb. We met face-to-face, and we started talking about the importance of just keeping in touch with each other.

There were very few programs, really, worldwide. She introduced me to some other people in the field like Lizzie Chambers. She was running ACT [Association for Children's Palliative Care] at the time. David Praill, he was running what is now Hospice UK. There was a global conference in Seoul, South Korea in 2005. I was invited to go and speak on advocacy. I was sort of doing advocacy at the time predominately around children.

When we saw the program, and I looked at the program in South Africa and Barbara Gelb looked at the program in the UK. We both noticed there was nothing about children on it. We both contacted the organizers and said, "There's nothing about children." They came back and said, "Oh, but children are always implied," which of course you should never say to anyone working in the pediatric field, as you know, because we said, "If they're implied, they get forgotten or tagged on at the end."
In the end, they said, "All right, you can have a preconference meeting. You can have a meeting during lunchtime." We persisted, and we ended up with having three meetings and people from 15 countries who came to those meetings all very enthusiastic. Barbara, and Peter Ellis, who ran Richard House, and he was the chair of Children's Hospice U.K. at the time. We stayed on for a few days to sightsee. We spent most of the time plotting how we could set up a network to reach people wherever they were doing pediatric palliative care and to really promote palliative care for children and the voice of the child because we recognized that we were all doing this from professional backgrounds. Where was the voice of the child?

Definitely from actually working with the children to working at national level and to developing the International Children's Palliative Care Network, which was in 2005 in Seoul, South Korea, that the whole concept was plotted. It really grew from there. A little bit in between, I then moved to become the first pediatric palliative care manager for the Hospice Palliative Care Association. Because I was working so much on children, they said, "Well, you might just as well just do Children, Joan."

We developed a national program where we went from 6 programs looking after children to 63 in 3 years through education and leadership. We had U.S. funding. We had a lot of paid-for funding at that time and Diana, the Princess of Wales Memorial Fund funding. At the time, this AIDS money, once we got past the president, was coming into the country. We could actually do things like that.

[00:29:37]  
**Bryan Sisk:** When you look at the adult hospice movement and the history of that, part of that drive was really a social drive. It came at a time when a lot of—at least in the U.K. and in the U.S., there was a lot of push for people wanting ownership of their own health care, just like they wanted autonomy. There's kind of this external drive. What was the driver for children's palliative care?

**Joan Marston:** You mean internationally or in South Africa?

**Bryan Sisk:** Both.

**Joan Marston:** Okay. I think the driver in South Africa was definitely HIV/AIDS and the coming together of large numbers of children who were dying. Hospices and, of course, health care professionals seeing these children saying, "We've gotta do something different." Once
we got past our political barriers, this large amount of money that came in, it allowed us actually to dream big. Our hospices blossomed. They really grew and developed and because we now had this funding. I'd say probably in the whole of Africa or Sub-Saharan Africa, that was the driver.

If we go internationally, I think it was a number of places having a realization that children were being left behind. It was really on the coattails of the hospice movement. The drivers of the adult hospice movement also drove the children's hospice movement. As I say, I think it was a number of individuals saying, "Hey, it can be this wonderful movement for adults. Why can't it be adapted for children?" Of course, one of—I don't know if you've found this out, but speaking to three of the great leaders of pediatric palliative care, Sister Frances Dominica, Richard Hain, and Ann Goldman, all went to Cicely Saunders with the idea, and she actually said to Sister Frances, "Don't do it," and then didn't encourage Ann Goldman or Richard Hain at all.

While she wasn't all that encouraging—and there was this movement that we could move into. Of course, the other great friend that you probably also discovered in your work, was Elizabeth Kübler-Ross. She originally wanted to be a pediatrician and had a great love of children. She was also pushing for children. It wasn't pediatric palliative thing. It was more pediatric hospice or children's hospice, but I think it was—as I say, I think passion around the globe for hospice also impacted on children's hospice, but there were also individuals who were passionate.

[00:32:45]

**Bryan Sisk:** From your perspective, was there a big societal push, or was it mainly professionals that were seeing upfront the suffering of children that were making this push?

**Joan Marston:** It was both. If you look at—I think in the beginning, you had people—if you had spoken to Sister Frances Dominica, it was her background as a pediatric nurse working with the families. From society, it came from the families, families who'd lost children or had seriously ill children working together with professionals. A lot of the movement that I've seen has been this combination—yes, you might've had that one visionary, but it was this connection between the families of the children and then of course the fact that children do [distorted audio 00:33:40] and that people do respond and getting this good community response because the needs of the children were finally highlighted.
While we look in children's hospice at the big names, a lot of the movement—if you look at children's hospice across Scotland and a number of children's hospices, it came from the community, but the suffering community, the community that experienced either the death of a child or living with a very sick child.

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**Bryan Sisk:** Personally for you, what were the biggest challenges you faced as you forged this career in children's palliative care and hospice?

**Joan Marston:** First of all, it was connection from the beginning. I think it would be so much easier these days because it's so easy to connect with anyone, isn't it?

**Bryan Sisk:** Yeah.

**Joan Marston:** In those days, it wasn't quite that simple. We didn't have WhatsApp and all of these things that we take for granted now. In the beginning, it was really—it was finding out where everyone was. The other challenge in the beginning was the lack of literature, the lack of training materials, and that we were sort of developing on our own quite independently. Although when we started in South Africa, I managed to get Richard Hain to come out and help that and people to come in to talk to us as well.

Then I think the other challenge was, again, going back to the lack of communication. It was almost as though the UK was one group working as such with Europe, and America and Canada were like over there. They were developing in their own way. There weren't these strong connections that we see now. The world is much smaller in pediatric palliative care. Even if you talk like in Italy, the way pediatric palliative care developed there, it's very Italy-bound in the beginning, although it's impacted on the whole global development now, of course, tremendously.

I think it was communication was probably our biggest challenge in the beginning. Once we started and got the money from PEPFAR/USAID, Canada, the Diana Fund, all of those, money in the beginning wasn't a challenge. It was free. It was available. It isn't now because those funders have sort of fallen away, but that was the challenge. It's a big, big challenge with getting the traditional adult hospice palliative care people to accept the pediatric palliative care group seriously.

In the beginning, it would be, "Oh, that's the kids group over there. They've been going on about kids again." It took us a few years for them to really say, "Well, we can't do anything without involving
pediatric palliative care." In the beginning, some of our adult palliative [laughs] were a little bit of a standing block, but they came around.

I've heard from talking with some people that there's different views on whether children's palliative care is part of the continuum of all palliative care where there really isn't a true distinction of "This is children. This is adult." I've heard others where their view is that there's a very clear distinction where there's pediatric palliative care, which is unique skills, unique training, et cetera, et cetera. How have you seen that? What are your thoughts on that, and how have you seen that develop over time?

Well, you know what, I have seen this, and I'm one of the group that believes that pediatric palliative care does need its own field. Pediatrics is a field on its own, so why pediatric palliative care should be seen as not being part of pediatrics, I've never been able to fully understand. What I've seen is that in countries which are more resource-rich, they've been able to develop pediatric palliative care apart from general palliative care. In places like Sub-Saharan Africa, India and other developing parts of the world where I've worked, it's been—because resources are limited, we have to have everything together simply because we can't afford to have a pediatric program and an adult program.

I think that—but that's changing as well because if you go into Eastern Europe, they are developing their—they have independent pediatric palliative care programs. I think part of it was, in the beginning as well, is that the—and again, I mean, I've got the dearest of friends in the adult palliative care world, but in large, it was almost like a big of—well, we don't want resources, which are limited, to go into pediatrics because everyone likes children so much. We need to, maybe, include them in general palliative care, but to me, it's been a difference in resources that have led to the different movements.

You mentioned Sub-Saharan Africa and India. Is there a tension between the children's and adult hospice in terms of competing for resources?

Definitely when it comes to competing for community resources, there has been tension. In the beginning, when we had the HIV, it was a worry among the more adult hospices that a lot of the money would go to children's palliative care. There's very few, very few groups that have ever funded pediatric palliative care from an international level. Our biggest and the leading one, of course, was
the Diana, the Princess of Wales Memorial Fund, which closed a number of years ago. That was a great loss to pediatric palliative care, but I think there was a worry about resources being divided.

People would get less resources if we had individual children's programs, but if you look—there's some wonderful children's programs in India. One of the projects that I ran through ICPCN was developing children's palliative care in India and Malawi, but they tend to be run alongside adult palliative care. It's a better use of resources to have your basic staff able to look after both groups. Same in Africa—you've got limited resources, so if you've got one doctor that you can depend on, that doctor's got to be able to look after adults and children, and the same with your nurses and your other staff as well.

I think resources have definitely played a role, but also, I think your early pioneers for hospice were more adult-focused. It was almost as if you were like "this was part of us that might be breaking away, and we don't like that." Certainly, when we started the ICPCN, it was very much, well, "let's keep it within the context of the worldwide"—well, it became the Worldwide Hospice Palliative Care Alliance, because we don't want it to break away. We don't want resources to go into an international children's program.

Later on, they realized that we needed to be independent. In fact, they kicked us out, which was a shock because we were quite safe and happy within the WHPCA [Worldwide Hospice Palliative Care Alliance]. David Praill one day, he had wrote me, and he said, "I think it's time that the ICPCN became independent," because I think they'd realize that there was a need for this specialist group.

How did that transition go?

Well, as I say, quite apart from the shock when I felt that we were being kicked out, the transition went very well because what we started with, the ICPCN, is—because we weren't that many of us working in the field around the world, what we did is go out there and Peter sat and saw—and we said, "Well, who do we know who's in India that we can involve? Who do we know who works in the field?"

This group of what we call the steering group were basically people that we knew. Then they went on and became our first board when we became independent. The transition actually went very well. The adult groups stopped saying, "Oh, it's just the
children's group over there," and they started recognizing us as a global network and not just an offshoot of the adult group. That went well. Some of our greatest supporters came from the adult group as well.

[00:43:19]

Bryan Sisk: What do you think were the most positive influences that the adult hospice movement had on the development of pediatric palliative care?

Joan Marston: Well, I think, from the adult side, it was the whole conflict, the whole division of what hospice and palliative care was because the principles are the same. Whether we're working with adults or with children, the principles of palliative care remain the same. It was their development of the field. Their development of a field that was being recognized as associations that we've been able to develop that. I think the advocacy, the development of, of course, the IAHPC and WHPCA, which influenced WHO and government.

It's allowed us to come in behind them in the beginning because we were behind them. We didn't start at the same time, we started afterwards. The WHPCA, especially, was very nurturing of the ICPCN. Once they realized that we weren't competition to them, they nurtured us. Then of course they—the research they were doing, the development of materials. Once you got the Oxford Textbook of Palliative Medicine, it really opened the way for the Oxford Textbook of Palliative Medicine for Children.

Then we had, like our GPs [General Practitioner]. I've always said I think we've had some amazing GPs who have really opened the field up. Being GPs that were working with adults as well as children, but if you look at people like Dr Satbir Jassal at rainbows Children’s Hospice and Dr Pat Carregger in Scotland—they were GPs who came from a family medicine background working with adults and children and who've made a huge impact on the development of the field.

[00:45:30]

Bryan Sisk: Were there any negative influences from the adult hospice movement or ways that the adult hospice movement held back the development of pediatric?

Joan Marston: I think in the beginning, I wouldn't say there were negative influences, but there were—as I say, Cicely Saunders, who in the beginning, actually tried to hold back the development of a separate field for children. She didn't feel that there was a need for a field for children, a hospice field for children. Then, of course, in
the beginning, the funders had to be persuaded that there really was a need to specifically fund children as well.

Those were challenges. I don't think now—I think it's another level—the thing with WHO [World Health Organization], because children have already been a large part with maternal and child health of WHO's work. In the beginning, it was getting the more adult, the more traditional hospice people, to recognize that children are different. They have different needs. As I've said, the funders as well.

Then getting something like children international policies as well. Italy led the way on that of course. Getting the church involved. It's taken a long time, so anything in the beginning with health care with Sub-Saharan Africa, the church was heavily involved. It took a while for the churches to get involved specifically in palliative care for children.

[00:47:20]

Bryan Sisk: Why do you think that was?

Joan Marston: Well, I think, again, it was a numbers issue. If you look at chaplaincy for children in the churches, it's a very small part of what they do. The numbers of adults are just so much bigger than the numbers for children. I think that's a big part of it is that we are a smaller group. The biggest always tends to get the attention. I think it's just genuinely a lack of awareness of what children's palliative care is about.

Then, of course, the Maruzza Foundation worked with the Vatican to get the charter on the rights of the child to palliative care. A lot more churches—when I talk about churches, I'm talking about big faith movements—churches on the ground, too, who've always helped and supported the hospices. That really set in this needs to be part of what we need to be looking at.

[00:48:25]

Bryan Sisk: If you look over your career, what do you think have been the biggest changes in the care provided for these children who are suffering and dying?

Joan Marston: If I'm looking at it from a purely African point, Sub-Saharan Africa, of course it was the antiretrovirals which changed things. I think the big challenges have been developing the field to be seen as a professional field. It's been developing professional training and education, and along with that, the research and the materials that go alongside with it. I think those have been immensely important.
I think the ICPCN has had a great influence because we've worked in—we have membership now in 125 countries. When I left as—I became the CEO of ICPCN as well. We had online training courses. We had practical training courses that were going on in all the different regions of the world focusing on the developing world. I think all of those are factors, but I think developing the ICPCN was probably one of the biggest things that we did from a global perspective.

Having the particular vision of the ICPCN, one, was communication, that how do we set up good communication with people in all different parts of the world on different levels of development of pediatric palliative care, with different understandings of pediatric palliative care? How do we get these connected? The ICPCN managed to do that in quite a good way. The advocacy, the fact that we could advocate at global level because we were a national network.

Then of course the education that we did in our online training, which reached a number of countries and was translated into many different languages. Later on, the research. I think one of the most important things was going to UNICEF [United Nations Children's Fund]. That was, again, one of those magical moments. I'd been saying for a long time that I want to know how many children need palliative care, but I don't want mortality statistics because our children live—many of them live for many years. We need to see what is the picture of children living with life-limiting conditions.

I was actually in Washington at an AIDS and living with HIV conference. UNICEF was there was well. A friend of mine set up a meeting. Literally within an hour he had agreed for UNICEF to work with ICPCN on a research project to identify the need. I'd spoken to one of the funders who was closing down and also the Diana Princess of Wales Memorial Fund. Basically we got this little bit of money that we then put into the pot. We'd phoned the True Colours Trust and said that we need this much more.

They immediately said, "All right, we'll give it to you." Literally within about an hour, we had agreements from UNICEF to do the research, and we had the funding to do it as well, and when we got—those results have also been fantastic for us to use for advocacy purposes and working with UNICEF as well. I think that was also a very important development in the research that we did.

Bryan Sisk: Absolutely. Who did you work with on that?
**Joan Marston:** Craig. I'm trying to think what his full name is now. He left not long after we'd actually got the money and got the project started. I'll think of his name. It was Craig, but of course, he had another group of people who were actually working on—then our PI was Stephen Connor, who of course you know, and Chenjerai Sisimayi, who was from Zimbabwe. We had Chenjerai doing the actual—the articulation on the ground because we focused on three countries, and later, we extrapolated to other countries. Then Stephen, as the African principal investigator working on the statistics and the records and the reports.¹

**Bryan Sisk:** Wow. What a legacy already. What would you say—

**Joan Marston:** As I said, that was just one of those—the stars aligned.

**Bryan Sisk:** It's funny. I think when you look back at history, it's easy to connect the dots when you're looking backwards, but looking forwards, I imagine that this might not—

**Joan Marston:** When you look backwards, absolutely.

**Bryan Sisk:** What would you say looking—

**Joan Marston:** At the time, as you say, it was—mm-hmm?

**Bryan Sisk:** What would you say are the biggest challenges both in South Africa, but also internationally? What are the biggest challenges that remain for the field of pediatric palliative care?

**Joan Marston:** I think that if we look at a global level, there are so many competing priorities, everyone from WHO to the UN [United Nations]. The pediatric palliative care, even though we think it's a big number, it's 21 million children, it's actually a very small number in comparison to the needs of children around the world. If we're looking at the funding to go into pediatric palliative care, it's never going to be a top priority, even within health care, because our numbers just aren't big enough.

One of the other groups that I helped to start up is PalCHASE [Palliative Care in Humanitarian Aid Situations and Emergencies] because just before I left ICPCN, I put out the question, “What's happening to palliative care in humanitarian situations?” Of course,

the answer that came back was virtually nothing. There was the odd bit going, and so we set up PalCHASE, which is Palliative Care in Humanitarian Aid Situations and Emergencies. I'm putting a lot of focus on that now. We've got all these humanitarian situations around the world which all are competing factors when they're looking at things like resources and funding.

I think our education has got to get out much further than it is now. We're doing well, but when we're going to a country, you'll find isolated programs. I work a lot with Ukraine and Georgia at the moment, and they're both doing fabulous things, but again, it's a bit of a drop in the ocean. Yeah. I'd say our biggest challenges are gaining the resources but realizing that, in the big picture, we're never going to be a top priority, and not in pediatrics, either.

**Bryan Sisk:** Have you noticed that there are—

**Joan Marston:** We do need a big funder.

[00:55:48]

**Bryan Sisk:** Have you noticed that there are growing international collaborations on this work, or does it seem like countries are largely siloed where they're primarily working on their own country?

**Joan Marston:** No. I think there's growing collaboration. I think the fact that we do have international conferences where people can come together. There's a number of international collaborations on research. We've been putting together a textbook of palliative care for children. I think it's a big collaboration. There've been partnerships that have happened between children's hospitals and children's palliative care programs in different parts of the world.

I would say there is a decent—a growing collaboration and a recognition that we have to work together to raise the profile of our children's palliative care. It took us 15 years, almost, to really get children's palliative care really recognized. I think the work that you're doing and the history that I've been putting together are really important because people are being forgotten who were actually major movers and shakers in moving the field forward. I think we do need to tell these stories as well.

I think we've been quite good at having the voice of children and young people heard, which the adult groups have now copied, which we've been saying for years they should do it. I think challenges, yes. I think there's a lot of things. Challenges can be overcome because we are collaborating. We are working together.
We are getting together at these global conferences, the one in Rome, the ICPCN conference, Richard Hain's Cardiff conference, and then of course the Children's Hospice International and Tomasz Dangel's workshops in the Warsaw. They have a real good foundation of getting people together.

Bryan Sisk: When you look at the field internationally of children's palliative care, what do you think is the strongest area of the field? Another way of asking it, what gives you the greatest hope when you look to the future?

Joan Marston: I think the collaboration, the fact that people are working together. You don't feel now that it's the North Americans in one place and the Latin Americans somewhere else and Europe and Africa, that in fact, we are feeling now like a global field. I think that, to me, is quite magical. The fact that as a global field, we have been able to be part of the influencing on WHO, and that the children are always included now. There's always a special mention of palliative care for children now. Those give me a lot of hope.

The fact that our education is developing and we are getting the materials and that when you go to palliative care conferences, it tends now to be a pediatric track instead of just one or two presentations within the whole course of the conference, that there is a pediatric track. I think that we are listening now even more to the voice of the children and the young people. All of those things give me a lot of hope. I'm very excited about the future. I think we've got fabulous younger people coming through with the passion, with the vision, and the dedication. We've got a good group to take it forward.

Lastly, I'd love for you to dream aloud. We talked about a lot of barriers, but if budget and politics and everything else we talked about was not an obstacle, what would you want internationally the care for these children to look like in another 10 years?

Joan Marston: I would like pediatric palliative care so integrated into the health care system that it wouldn't be seen as something that is extra, and it would be nice for a few children, but every child who needs palliative care would get this. They wouldn't have to travel many miles to go to either a hospice or a pediatrician that does palliative care, but it would become just an absolute integral part of universal health coverage so that it would be accessible to every child's needs.
[01:00:40]

**Bryan Sisk:** Those are all of the questions I have, but I'd be very interested if there's anything from this history that you think I haven't hit on that I should know about?

**Joan Marston:** No. I think you've hit on all the important developments, I think, and I love your hope for the future as well. Not knowing who you've been speaking to is—makes it difficult, but I'm sure that you've been able to identify all the major leaders in the field as well. I think the whole collaboration around, maybe, pediatric palliative care fellowships, which are very strong in the U.S. The rest of the world is very, very much behind the U.S. in this because while we do need to have every single generalist to have an understanding and be able to do basic pediatric palliative care, we need our specialists. We just haven't got nearly enough of those. I think that maybe the whole areas of developing more specialists in the field.

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