



*A refuge for unborn-newborn babies
and little children who will die and
those who love them*



FALL 2021 NEWSLETTER

Editorial

Dear Friends,

We hope this finds you all well, in these still uncertain times, and able to at least enjoy some lovely fall weather and the bounties of nature. In this issue, we have the privilege of hearing from Kathleen Currie, who tells us the story of losing one of her twins, John, but welcoming into the world his identical brother, Patrick, and knowing the full spectrum of both grief and joy in her boys. We mourn the passing of Martha Hubbard, a great friend of Alexandra's House.

We also hear from Dr. John Stroh who is a pediatric palliative care physician at Children's Mercy Hospital. Although I joke to friends that John is the kind of person you would like to meet socially, but NEVER professionally (he's my husband so I can say that kind of thing), I'm always conscious that for those of us who have been, are or will be caught up in those most tragic moments of family life, having a physician who cares immensely and sits with you in your darkest hour, is an immense gift. Although I often hear snatches about his day-to-day work, it was a real privilege to sit down with him and interview him at length about what he does and why he does it. It's not for everyone, and I know our family sacrifices time with him because of the gruelling demands of his work, but I am grateful for what he does to bring light to the suffering of families in the region. And I am grateful to Patti without whom his own journey to this specialism may not have become clear.

-Hilary Stroh



Interview with Dr. John Stroh

When you tell people you are a pediatrician, people's reaction is overwhelmingly positive but when you say you are in palliative care, people are either shocked or uncomprehending. Why?

The response probably stems from a narrow view of what palliative care is. There's a conflation of palliative care with hospice and end-of-life care. I think that's an unfortunately common misperception. It's true that these are a significant part of palliative care, but full-spectrum palliative care is so much more than that. In the world of pediatrics, we are more likely to get to practice full-spectrum care than our colleagues in the adult world.

How would you define palliative care?

I would point people towards the WHO's definition which is very good – total, holistic care for a child, physically, emotionally, spiritually, psychologically as well as care for the family around them. In short, a family- and community-centered approach to care, a recognition that suffering is not just physical, but emotional, spiritual and even existential. Our care as physicians is focused on providing support and finding ways to relieve suffering.

There are other components of that definition that are worth highlighting – an acceptance that death is a part of life, a normal part of everyone's life, and this, of course, is very compatible with our Christian point of view.

To move from definitions to your experience working with families in tough situations, what keeps them together as individuals and as families – how do they cope?

In the conditions where there is uncertainty – rare conditions, those with a broad prognostic spectrum, that very uncertainty around prognosis allows families room for hope – maybe initially hope for a cure, for an outcome on the better end of that prognostic spectrum, or hope that their child will beat the odds.

But even if the course goes along, and the family finds that their child is on the worst end of that spectrum, one of the things we do as a team, is to help families find new or different things to hope for – reframing hope, or 're-goaling', a phrase one of my mentors coined.

Can you give me an example?

Sure. Say a child who has a cancer – the initial hope might be for cure, for disease-free, long-term survival. Maybe the child has poor response to treatment, or has a relapse, and it becomes clear that cure is no longer a realistic possibility to hope for, the goal could be living to a significant milestone – say a high-school graduation, being able to take a long-dreamed of family trip, the vacation to

Hawaii while the child is still physically able to tolerate travel, and to be able to physically enjoy the activities on a trip.

And does your team help families to articulate those goals and also to make them happen?

We certainly prompt a family to think about 'what else can we hope for?' and we work towards helping families achieve those alternative goals. We are not travel agents who can book airline tickets to Hawaii, but we can give the green light, set them up with the medical equipment they need, make sure that they have contacts with our colleagues wherever they are travelling to, so if there is a symptom management emergency that arises, there is someone who is familiar with their case, and there's a number they can call to get the help they need even when hundreds or 1000s of miles from home.

And I suppose, above all, you give them permission to dream those dreams?

Yes. And honestly communicate when the goals they had been hoping for seem less realistic or when the window seems to have closed on those.

Is that honesty the most difficult thing about your profession?

It's hard to give people bad news and I think it's something that is naturally very easy to shy away from.

How do you have those conversations, the ones no-one has ever wanted to have?

There's a lot of upstream work in a lot of cases – trust-building, rapport-building, so that the family knows that we are there to support them through good and bad, so hopefully there have been occasions for us as a team to celebrate with them when things have gone well, so ideally, we aren't just showing up when the news is bad. And once we become familiar, trusted faces, the honest delivery of bad news is much easier both for us, as clinicians, but also much easier for the family to receive from somebody they know is in their corner, on their side and wants the best for them and their child. It takes time, it takes preparation, the right setting, a warning shot so that they know what's coming, clear jargon-free delivery of the bad news headline, and ideally silence to allow the family a chance to hear it, to start to process it, to respond to the bad news with whatever emotions they have at that time, to attend to those emotions, and to avoid the temptation to keep talking, in the face of our own discomfort. Silence can be uncomfortable. The risk is to over-talk.

Speaking about emotions, obviously the family's emotions are the primary concern, but your own emotions as a physician

are in the mix. it's an enormously taxing field, emotionally as well as ethically, and burn-out is very real. How do you create boundaries so as to stay grounded, and keep the necessary separation so you can continue to do this work day after day?

To a certain extent, people who have gone into the field have self-selected, have recognized that high degree of emotional intensity, and the need to take care of oneself. Now that there are palliative care fellowship programs and board certifications, there's a certain degree of screening in the interview process, to make sure that this is a trainee/employee who will be able to sustain this work.

And in your own case, is it easy to turn off that switch or does it bleed into the rest of your life?

That's something I recognized I was able to do effectively enough to go into the field. There was a gradual step-by-step process of approaching pediatric palliative care and making sure it was a good fit, and I could sustain it throughout a care, and care and be compassionate, but not bring it home and stay up at night worrying and not being able to let go.

Has there been any situations that made you weep? I remember some people on our care team weeping for our loss, and I thought it was so powerful, that these professionals would show their emotion, and share with us, perfect strangers, the tragedy of our dying baby.

The emotions certainly well up when I'm present at birth, and especially at a baptism – immense thankfulness that parents get to meet a new baby, even if for a short time, joy at hearing a cry, if there is one, moved to see parents demonstrating their love for the baby.

Tell me, has your job changed the way you see the world?

I've become more acutely aware of the limits of medicine, science and technology, more skeptical of technocratic claims that we can ultimately solve the problems of human suffering and death. I appreciate more that we live in a fallen world. I think I'm more relaxed about parenting, because the things I see in the hospital put my own struggles and my children's in perspective.

What is your basic ethical framework for palliative care?

Palliative care, in the phrasing in WHO 'intends neither to hasten or to postpone death'. That's a core principle. Sometimes, you do get into the doctrine of double effect – if the intention is to provide relief of symptoms, it is permissible to accept risk; but the intention is not to hasten death. Unfortunately, there is a movement (more in the adult palliative care world) towards the legalization of euthanasia, but that's not something we really encounter in pediatrics.

The US Conference of Catholic Bishops have published a helpful set of ethical directives for health care, informed by Vatican documents, which have been vital to my own foundation.

Before we close, I'd like to hear what I always think is one of your most moving stories, which for me illustrates the best of palliative care. It involved a young lady in the DC area, who had recently moved from sub-saharan Africa. She was a nanny, but found herself suddenly unemployed, without proper housing, and expecting a baby with a diaphragmatic hernia in the setting of a genetic condition. Can you tell me the story about the journey that woman made?

She was followed by Holy Cross hospital in Maryland, who had a wonderful program that I hope other hospitals offer, where women with high-risk pregnancies are accompanied in a very holistic way, and are given holistic support – a good example of culture of life in microcosm. Like many mothers we meet prenatally, she had a degree of fear about what her child would look like, and how she would react to her child dying in her presence. She was brave even to articulate that, as lots of people experience this, but are afraid to articulate it because they don't want to come across as bad parents. The team gave her space to share what she was feeling. We normalized her fears, and addressed them, assuring her that nobody would force her to hold her baby, but instead tried to paint a picture of what the baby's few moments would look like after birth, how he might take a few breaths, but might not cry, how would be comforting for him to be wrapped up and held by her. In short, we gave her permission not to hold, but also to encourage her to bond and find togetherness. The baby was born – a very beautiful baby, looking just perfect – and his mother held him dearly for the few minutes of his precious life. Afterwards, she was so grateful to us that she hadn't missed out on these extraordinary moments: she wouldn't have had it any other way. Care didn't stop there. Her dream was to return home to Africa and the hospital was going to help her to get her to where she wanted to be.

That's certainly as beautiful a reflection on the power of holistic care as any I've ever heard.

I suppose we can't finish without mentioning Margaret. Your own daughter, how large does she loom in your decision to follow this vocational path?

There was a general interest before Margaret's time. The experience that we had as parents and care at the hospital encouraged me to explore the interest further, but it made me more cautious, at the same time, because of the personal baggage... I feared the work would be too emotionally intense for me, a constant reminder of the pain we went through. Hence the cautious step-by-step trying out of the field.



Kathleen, we're honored to hear the story of your baby twins. Knowing you were expecting two baby boys must have been an amazing gift - and then suddenly, the nightmare news that there was twin-to-twin transfusion. For our readers who might not know, can you share with us a little of this?

I found out at 7 weeks that I was pregnant with twins. I was at my OB because of severe abdominal pain and they did a sonogram and found two babies. I am very blessed that my doctors know I naturally carry high risk. They were quick to onboard supplements and hormones to maintain the pregnancy.

I can remember feeling so nervous and excited to be carrying two babies. There was a lot of unanswered questions that a lot of women deal with such as "where will they sleep?" "What will I do for childcare?" "Will I keep working?" What would take place in the following 23 weeks never crossed my mind.

I was referred to a high-risk Doctor through Olathe Med who in turn sent me to Children's Mercy Fetal Health. I had read a bit about Twin to Twin Transfusion but didn't understand it fully. Twin to Twin Transfusion Syndrome (TTTS) occurs among twins that share a placenta. My Twins were Mono/Di twins, meaning that they shared a placenta but had separate sacs. TTTS is when the blood vessels in the placenta fuse together and the babies begin sharing blood and nutrients. One baby becomes larger than the other baby and it results in losing one if not both babies. There is a procedure that can be done to laser the abnormality but there must be a weight discordance of 20% and the most my boys ever had was 17% so they never qualified for the procedure.

How did you cope, and where did you find support and strength?

The whole pregnancy was tumultuous. I lacked support from my former spouse and my family. When the time came to grieve and work through the pain I felt like I had no one. My crying made my family uncomfortable. No one was able to listen or care for me. Since one of the twins did survive, I would repeatedly hear "at least you have one." Those words made me feel guilty and horrible for having these feelings.

I found my support when I spoke to Diane Cheek and she encouraged me to go to Alexandra's House. I won't forget that day that I met Patti and I finally felt like I could breathe. Our one-on-one conversation gave me hope that I could work through these feelings and gain support. I didn't formally start attending groups until after Patrick came home.

How were you able to develop a relationship with your unborn twins? Did you name them?

I felt very connected to the twins. Even when I was pregnant, they each had their own personalities. I had appointments at Children's Mercy twice a week, every week, for 23 weeks. They would take measurements and get readings. The sonographers were amazing and would take video so I could show my kids. I have dozens of 3D and 4D imaging. The boys would play with each other and be ornery. At 19 weeks, I was taken to an office room and they began making a health file for the boys since we never knew when they would be born. Baby A became Patrick Jerome and Baby B, John Killian. I wanted good strong Irish names. John is named for my Uncle John and Patrick, well let's just say I am a big Chiefs fan.

Tell me about the birth and their story, and their different trajectories and the care at hospital, and navigating being a new mother in circumstances of such emotional intensity and hardship?

At 29 weeks I had abnormal fetal movement. I waited until my next appointment to talk to my doctor about it. On February 25th at 30 weeks, I went in for my regular appointment. I had done this routine so many times but that day felt different. The sonographer immediately got Patrick on the monitor and rolled over to John and quickly took the Doppler away and said "I can't get him on the monitor. I will be right back." My doctor returned, checked Patrick, and looked at John and said "I am sorry this baby has passed". I felt like I had failed and started crying. But the doctor insisted that I had to have surgery fast to get Patrick out. My nurse Courtney stayed with me while I was prepped for surgery. Their Dad arrived to the hospital and went into surgery with me. Everyone was so kind and gentle with me. Patrick was first to be born and cried immediately. It was music to my ears to hear him cry and know he was alive. He took John next. They wrapped him up and allowed me to hold him and kiss him. He was only 2 lbs when born and Patrick was almost 4 lbs. Patrick was intubated right away and sent to the NICU.

When I returned to my room I was bombarded with nurses and family specialists "checking on me" I held John a little longer, requested for them to do a baby photo shoot with both boys. The pictures turned out beautiful.

Once I let them take John's body, the second leg of the journey began. Patrick spent 57 days in the NICU. 53 of those 57 days, he had bradycardia and would require resuscitation 6-12 times a day. He was also anemic and required 2 blood transfusions. I was very

blesSED to have the nursing staff at Children's and two very dedicated nurses for Patrick. Having the primary day nurse and night nurse was great because they knew me and Patrick. The hospital became our home. It seemed like everyone knew who I was from the guy at the coffee shop to the Doctor at rounds. I got comfortable going every day to hold my baby all day long. I would bring him books to read, sing songs to him, or even just talk to him. At 3:30pm I would pack up my stuff and go back home to my other children.

It was survival mode - trying to keep my house afloat, keep Patrick alive, and allow myself time to grieve for John. On April 21st 2019 the Doctor at rounds told me Patrick was coming home on Friday, April 23rd. I didn't believe him. I had heard this before and had the rug pulled out from underneath me. On Thursday, the 22nd they took him off all his machines and leads and we stayed the night together in a separate room, I was fearful for him to not be hooked up and monitored. Once we were discharged, it became real. I put him in my car and drove us home. Diane was at the house and it filled me with so much joy for her to be able to see him with my other kids.

The third part of my journey was the grief process. Letting myself feel my feelings and finding solidarity with the other Mom's at Alexandra's House. I had felt alone for so long and my relationship with God was deeply strained. I felt like I was able to start talking with other women who understood that grief is more than death, it's planning the baby's room, it's returning things to stores, it's breaking the news to friends and family, and it changes a person.

Where are you now - after having gone through so much?

I am at a place of balanced in my journey. I have accepted and acknowledged my tumultuous pregnancy, the loss of my son and the sweet little boy who survived. I still take time to feel and grieve when I feel like I am missing something. That feeling is lasting. This longing and feeling of something missing from my life. I know it is John's presence that I miss and long for. I live my life everyday with the mindset that nothing will stop me from getting to heaven so I can hold John. I take joy in all of Patrick's antics and he is so wild and full of life.

I do take off work the day before their birthday to grieve and feel all the emotions and on their birthday. I make it my day of service. I take donuts to my coworkers for all of their prayers and meals they sent to our home and I have a mass said for the twins. By allowing myself the time to grieve the day before I am able to enjoy and celebrate Patrick's special day. We do sing Happy Birthday to both boys and during the holidays we put up a stocking for John.

The best part about identical twins is, I will never have to wonder what John would look like. He is identical to Patrick. Same smile and eyes. I look at Patrick and I can feel that twin love and energy. So right now in my life I have a sense of peace and balance.

The community of Alexandra's House would like to mark the passing of one of its dear and faithful supporters, Martha Hubbard, of Lenexa, Kansas, and co-founder of the local annual bowties for Babies Gala which provides financial support to the mission of Alexandra's House. Martha died at age 81 on September 10, 2021. Born in 1940 in Yonkers, New York, she graduated in the sciences, and met her husband Johnny at West Point Military Academy. They were married in 1962 and led a career in military life. Martha supported her husband, four children and country through multiple moves until Johnny's retirement in 1988, when they settled in Lenexa, Kansas and became members of Good Shepherd Catholic Church.

To Patti and those who serve Alexandra's House, Martha will be remembered and appreciated as an epitome of femininity and grace. It was delightful watching Martha and Johnny dance; she in a soft-hued gown and he, dashing, in a black tuxedo. All are deeply grateful for Martha's advocacy for Alexandra's House, her immense generosity, and the warmth of her friendship. We would like to extend to Martha's family our deepest sympathy. Martha has simply moved on to serve in a new way. The Holy Sacrifice of the Mass will be offered for the repose of her soul and the comfort of her family.





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