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A Letter to Our Daughter

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To our sweet, dear, Roo.

You close your eyes when the doctors walk into your hospital room, and we wish we could do the same. Our hearts are empty without you at home. We invite your older sister into our bed at night to hold her close to comfort ourselves and remind her, despite her feelings otherwise, that she is still part of the family in spite of the time we devote to your care. We would do anything to take away your pain, to suffer your illness in your place, to give our life for yours.

Your illness has revealed us as frail and limited. We have difficulty maintaining objectivity as we can do with our own patients or adult family members. Our perspective is clouded by the unconditional love of parents. Through tear-filled eyes, we fear your uncertain recovery, the loss of your potential, and feel nauseated by our inability to protect you from suffering. Mentally and physically exhausted, we misread or misinterpret the medical literature; our minds reflex to catastrophe. We see your fear as you notice what is happening to your body. We realize that your 4-year-old brain understands every word, and we can no longer speak freely in your room to each other or clinicians. We are emotionally gutted.

We are advised to just be parents during your illness, but that is not possible. Medicine is as intrinsic to us as parenthood. Medicine is our culture. It has bridged us into a multicultural Hindu/Jewish family united by a common language and belief, a common sacrifice. It is what allows the attending physicians involved in your care to connect to us; they introduce themselves to us by their first names despite a lack of prior acquaintance. It is why the residents introduce themselves to us as “Doctor”, not having yet spent sufficient time as physicians to drop the pretense and understand the collegiality that deeply binds. It is why we preferentially reach out to friends who are medically trained for emotional support, with whom we speak in energy-conserving shorthand. They understand the unspoken; they don’t offer blanket reassurance that everything will be ok. It is why we posted your struggle to the Physicians Moms Group on Facebook, women linked only by the commonality of being a

parent and a physician, with a resultant outpouring of virtual and in-person support. It is also why we use caution when walking down hospital corridors, knowing that our presence in certain parts of the building out of our norm would invite questions we want to avoid or are not ready to answer from curious colleagues.

In the hospital, we tiptoe the difficult balance between advocacy and annoyance. We hope to not be labelled as “that family” into whose room clinicians dread to go. We debate whether to wear our hospital identification badge, wondering if that would be seen as a sign of entitlement and expectation.

We suggest consults and push for their completion early in the day, understanding the stakes of delayed diagnostic tests and procedures. We grow antsy during the purgatory of having been admitted to the hospital but being boarded in the emergency department while waiting for an inpatient bed, where delineation of patient ownership is murky, and worry that you have been forgotten. We anticipate the slowdown of clinical care over the weekend and debate if we push for further testing on a Friday, though the indication may be early, in fear of two days of inactivity. We ask the intern to not take the microbiology lab’s assurances on the phone that there is no fourth tube of cerebral spinal fluid, and to instead walk down to speak to the lab supervisor to confirm. We cannot imagine how anyone can navigate the medical system, when we, two physicians who have the flexibility of being able to drop everything to care for you, barely can manage.

Amongst the nightmare that your progressive illness has been, there has been some good, some levity.

We are the beneficiary of a truly family-centered care experience. We have received outstanding nursing care: smart, proactive, empathetic, efficient. Every interaction ends with us being asked what we need as parents, making our eyes mist as much as for the outward show of compassion as for the obvious answer- we need you to get better. The physicians spend hours caring for us; significantly more than the 35 minutes allotted for a level III visit. We have been seen by master clinicians: the emergency medicine physician who figured out what was going on within minutes of assessment; the radiologist, neurologist, and infectious diseases consultant who confidently confirmed the diagnosis; the pediatric hospitalist who expertly managed our emotions and your medical care. An army of child life specialists, physical therapists, music therapists, and pet therapists distract you better than we can and bring a smile to your face when we cannot. We are anchored by our relationship as husband and wife, one another’s principal support even though we are seldom in each other’s presence during our alternating 24 hour shifts on and off at your bedside. The pediatric sub-intern was a rotating medical student under one of us a few weeks ago and is now a member of the team coordinating your overall care, leaving us wondering (and hoping) that we previously spent adequate time teaching and just being nice to him.

There is a humility that comes with the daily practice of medicine. A perspective as to what is truly important in life, made more acute when illness lands close to home. We counsel our patients on coping with medical adversity: take it one day at a time, do not catastrophize. We

have realized that with our own child, it has been difficult to put this advice into practice, particularly as her clinical course seems to deteriorate.

To our sweet, dear, suffering Roo. You are perfect and a miracle in our eyes. That passport picture of you with your pigtails, red heart shirt, sparkling brown eyes, and mischievous smile is who we know you to be, as far away as that might seem currently. You deserve a mom and dad who are not overcome by their fear of present and future adversity. We will get our wits about us and be strong for you. As parents, we will be there, so you feel as safe and secure as possible. As physicians, we will use our medical knowledge and training to be your most rational advocate. We will adapt to a new normal, whatever that may be, with support from other parents and physicians: the ties that bind us to each other and our broader community. And we will remain hopeful for a time when we can all once again as a family revel in the mundanity of the everyday.