

Sample Package – Family Centred Care Advisory Council Humanitarian Award Nomination from Patient Family

This form should be replicated/copied on computer by the nominator. The numbering and heading system shown herein should be followed:

Name of Person/Team Being Nominated: **PAOLO CAMPISI**

Program/Department/Division: Otolaryngology Head and Neck Surgery
Mailing Address: 555 University Avenue, Toronto, ON
Postal Code: M5G 1X8
Telephone No. 416-813-2192
Email: paolo.campisi@sickkids.ca

Nominated by:

1. Name: **CHRISTINA CHARLTON**

SickKids Staff Member Patient Family Member
Program/Department/Division: N/A
Mailing Address: 525 University Avenue, Toronto, ON
Postal Code: M5G 2L3
Telephone No: 416-813-6166
Email: christina@rogers.ocm

2. Name: **SCOTT CHARLTON**

SickKids Staff Member Patient Family Member
Program/Department/Division: N/A
Mailing Address: 525 University Avenue, Toronto, ON
Postal Code: M5G 2L3
Telephone No: 416-813-6166
Email: scott@yahoo.ca

Name of Program Director or Department/Division Head that supports this nomination:

Name: Dr. Vito Forte
Position at SickKids: Chief, Otolaryngology Head and Neck Surgery

Please answer the following questions using as many examples as possible. Candidates about whom the Selection Committee has little information will be disadvantaged. Staff members or teams will have demonstrated some or all of the values listed in the questions below. The nomination should provide clear examples of how the individual or team has consistently demonstrated these qualities in an exceptional manner.

1. How long and in what capacity have you known the Nominee or Team of Nominees?

I would love to recognize a special part of the SickKids team in the ENT program, staff physician Paolo Campisi. My family has come to know him well through his wonderful care of my 15-month old son Jonah, though he has not just cared for my son but all of us.

At 2 months old, Jonah was found to have a laryngeal web. A rare condition where there is a tissue in-between the vocal cords in his airway. I knew as a nurse that when the fellow said "I have to get another doctor to look at this!" it was not a good sign...

Jonah would have blue "breath holding" spells thought to be temper tantrums at birth, then I noticed some noisy breathing at 5 weeks old and mentioned it to my pediatrician who referred us to ENT clinic where he was diagnosed with the web.

It was then that Dr. Campisi asked to send off for a genetic test as webs correlated with a genetic condition known as 22q11 deletion, though Jonah did not seem to have any of the other features. We were all surprised when it came back positive. If it were not for Dr. Campisi sending off for this test, I would never have known my son had this. No one suspected it, not even my very experienced pediatrician. Maybe it would have been easier not knowing, but I now realize knowing this is vital for me to give Jonah the best opportunities in life and to make sure he has all the resources available to him to reach his full potential.

During our admission in August, Jonah was supposed to be there only overnight but due to complications ended up being there 3 weeks including an ICU admit. Dr. Campisi mentioned to me that if he couldn't manage him with medications an option would be a laryngeal reconstruction surgery. This was a big surgery, very invasive and involves an incision to be made in Jonah's neck, his cricoid cartilage split open and having another bone grafted in place to make it physically bigger. The recovery required him to be intubated and paralyzed/sedated so he couldn't move for 7-10 days. I have to tell you, it scared the bejesus out of me. But we decided to let him grow and give him a chance.

In December he was admitted again twice, back to back and was recovering slowly. I knew in my heart that he was getting worse and I couldn't keep managing him at home like this, sleeping with one eye and ear open every night. He may not survive the next acute episode. I felt a part of me wondering if we should do the surgery, what if he didn't get help in time the next time? Dr. Campisi took the opportunity to approach the subject with me again. I was in shock and taken aback to have it presented to me, but I knew that is what he needed and denying that this would all pass. I now realize that Dr. Campisi also was waiting for me to be ready to know that this was the right decision for Jonah and our whole family. That we all needed to be emotionally ready to go through the operation. He took the time to talk to my husband and myself over and over again about it. It was time, he recognized that Jonah's illnesses were becoming more acute and taking longer to resolve in hospital and it was preventing our family from having a normal life. It was disruptive to our other child, our worklife and emotionally stressful as

well as delaying Jonah's development. It was actually he, who made me realize this, as I was so busy living from one illness and waiting on the edge for the next, not putting the big picture together. I realized Dr. Campisi was right.

Jonah is a month past his surgery now and we cannot believe the difference. He used to sit and play only if he can reach a toy. He had an incredible reach! A week after being home, he's crawling around so fast, he's into everything. I can't keep up. He's trying to take his first steps, he's laughing and yelling with glee, all things that he didn't do because he was spending all his energy trying to breathe before.

2. How has the Nominee/Team provided exceptional care, respect and attention to families while demonstrating an outstanding recognition and commitment to the needs of the family? (These values include understanding, respecting and supporting the pivotal role families play in the lives of their children.)

Through Jonah's admissions to the hospital, Dr. Campisi was always the constant through the stressful year. He would come up without fail every morning before his surgeries or clinic day began to see Jonah and found out how his night went, and again at the end of his day before he went home. If Jonah was misbehaving, he would come see him when he had a break during his day as well. I always let out a sigh of relief when I saw him come in the room. I always made sure I got up though I would have loved to sleep a few extra minutes as to not miss him, if I did; I felt a little lost the rest of the day!

Dr. Campisi always asked my opinion on how Jonah was and what is more important, he took it seriously. He always asked me how I was coping, how my husband was doing with all of this, and how my other son was with my absence. He never forgot to interact with Jonah as well and always "talked" to him first. Jonah has always had huge stranger anxiety but he would get very excited when Dr. Campisi came to see him, he would literally shake with excitement.

3. Show an example of how the Nominee/Team respectfully partners with the family, reflecting his/her/their understanding of the social, emotional, and developmental impact of illness and hospitalization on the child and family.

Dr. Campisi came to see us everyday in the ICU and kept us focused on our goal amongst the many issues that developed as one would expect to happen in the ICU over 8 days. I know there may be other challenges in the future but I cannot tell you what it means to know that Jonah will have the best possible chance for a healthy life because he has such wonderful people on his side. I knew that when Jonah went into the O.R. I didn't have the same fears as is normal when parents are separated from their child at such a stressful time. I knew Dr. Campisi not only had the skill to perform this risky surgery, but that he would treat Jonah like his own. I knew because of the time that he spent interacting with Jonah over the past year, building a relationship with him that Dr. Campisi's face was a familiar one to Jonah and one that he associated with someone who was always kind to him. That meant so much to me as the nurse took him away from me into a strange operating room.

4. Demonstrate how the Nominee/Team collaborates and communicates meaningfully and openly with patients and families seeing them as equally important members of the care team while supporting autonomy with patients and families. (These values include respect for, recognition of and support of the uniqueness of each individual child and family while creating a caring, supportive, transparent and welcoming environment for patients and families.)

Dr. Campisi's gentle bedside manner I know helped me get through many difficult times. He seemed to know when I was fragile but also know when I needed firm guidance and leadership and got my focus back. This combination takes much experience and sensitivity to develop. I always felt like I was part of the decision making process and I also felt confident in his care and decision making. It takes a special quality for someone with such immense knowledge and skill to lead with an air of partnership.

One day, Dr. Campisi bumped into us on the elevator and stopped in his tracks with his winter coat on ready to go home after a long day, happy he had the opportunity to talk to both of us as my husband came only after work to see Jonah and I. Dr. Campisi made time for us and took us somewhere to talk and to answer our questions like it was the most important thing he had to do at the moment. We parted knowing that it was the right thing at the right time. But it was Dr. Campisi's approach to the subject that made us feel it was so. He was always mindful that my husband did not have a medical background and asked his understanding and his feelings about everything and always took the time to answer his specific questions.

5. What differentiates this individual/Team apart from other staff in terms of acting above and beyond what is expected of them?

I was so very moved and grateful when he came in to see how Jonah was doing on an especially sad day for me, Christmas Day, I was away from my 4 year old son now for 3 weeks, and this was the first Christmas he really "got it", Santa, the tree, gifts, waking up Christmas morning. It was the first Christmas I was supposed to have with both my children having fun, opening up presents, taking pictures of all of us together. It was especially heartbreaking for me as we had difficulties having our second child and it always had made me sad that my 4 year old was always on his own, this Christmas he would have a brother to share Christmas with. Jonah was only 2 months old last year, but instead my 4 year old was alone with grandparents, and my Jonah was on the ventilator in the ICU, swollen and with a fever of 40C. Dr. Campisi was taking his own children to see The Nutcracker, a family tradition on his day off which I know are too few, he stopped in to see Jonah before the show started and it made me feel like I was not alone, and that someone other than myself cared and we were in his thoughts.

I am so grateful to have Dr. Campisi taking care of my son, I know for a fact that my husband and I have made it this far in many stressful times over the past year, because we had someone who we trusted and that we knew Jonah was always being cared for the best way Dr. Campisi possible. Even being up at our local hospital in the middle of the night where we are always taken to first after our 911 calls we never felt alone. Dr. Campisi has always said he is reachable anytime.

I am also an RN at SickKids, and have worked there since 1993, I have gotten to know many special staff members during my career but I feel so fortunate to have had Dr.

Campisi come into our lives. I know from personal experience that his special combination of medical skill and empathy for his patients' families is not to be taken for granted. He goes beyond the call of duty not just at stressful times but in his every day practice.

6. How does this individual/Team work with other members of the team/teams? (Examples would include how they collaborate and communicate meaningfully with all members of the interdisciplinary team; exhibit professional behavior tempered by humility.)

I have watched Dr. Campisi with other patients' families giving the same care and respect. I have watched him be respectful with the nursing staff, even my homecare nurse, a former O.R. nurse, when told Dr. Campisi was Jonah's doctor said "Oh yes! He was my FAVOURITE!* If you have the nursing stamp of approval, you know you've done good as a doctor! We're a hard bunch to please. I think Dr. Campisi should be awarded just for surviving having a SickKids nurse as parent! We are probably the worst possible parents to have, he has had to calm me down a few times. As you know, to us, it may just not be a cut, it may be flesh eating disease! It may not just be a headache, it may be meningitis!

7. Has the nominee used his or her professional experience in the Hospital to help the community and/or to advance family centred care practice? i.e. – is there anything that would be relevant to humanitarianism – for example, volunteer work?

Not applicable.