2005 Genetic Alliance Conference Awards Art of Listening winner

Luba Djurdjinovic, MS, CGC, Ferre Institute, Advisor to CFC International and others

The *Art of Listening Award* celebrates a health care professional who goes beyond what is required, takes the time to listen and understand, contributing a vast amount to advancing understanding of the disease, so that both treatment and research are accelerated. The nominator must give concrete examples of the professional's capacity to listen and serve the families suffering with the condition he or she treats. Brenda Conger, President of CFC International nominated Ms. Luba Djurdjinovic, MS, for the Art of Listening award in 2005. Luba Djurdjinovic is the program director and genetic counselor for the Genetic Counseling Program in Binghamton, NY.

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L – R: Sharon Terry, President Genetic Alliance, Luba Djurdjinovic, Art of Listening award winner, and Brenda Conger, President CFC International, who nominated Luba for the award

Nomination Article from Brenda Conger:

I first met Luba back in the 1970's during my mother's appointment as head secretary in the Biology Department at Binghamton University. She came home with many fond comments about Luba. Since my mother is no longer with us I cannot remember if Luba was a graduate student at this point or possibly a teaching assistant at the university. All I remember was that my mother had extremely kind words to say about Luba and this was not always the case with some of the demanding professors whom my mother worked for!

My next encounter with Luba came in the fall of 1992 while pregnant with our second baby. By then Luba had established her own genetic counseling business in Binghamton, NY and I had contacted her since we had lost a baby at 12 weeks and was attempting one last pregnancy.

After teaching in the field of special education and extensive work in the residential institutions of Pennsylvania during my college years, I knew I was not cut out to teach handicapped children all day and then deal with a handicapped child of my own at night. My husband worked late hours in his ski retail business and a special needs child was totally out of the question for both of us.

Making an informed choice with the correct information was extremely important to us. I will never forget the phone call from Luba. It was December 23, 1992 and we were approaching the Christmas holiday. Great news! The baby's chromosomes were fine and we would be having a boy to join little sister Paige!

In the weeks and months that followed, unusual medical concerns came up in my pregnancy. I developed polyhydramnios. The baby had a very small defect of ureter tube blockage on one side, but we were told this could easily be corrected up in Syracuse, NY after the birth. It was not until February 1993 with a due date of June 7 that I frantically put in a call to Luba to tell her that the ultrasounds in the hospital were not going well and the space behind the brain did not develop properly. In addition, the one ureter tube had totally blocked up and the other tube was semi blocked. My husband was away and Luba took charge of my situation. She immediately collected information and started right to work on further evaluations. She listened as I sobbed and had nowhere else to turn. After a trip out of town to obtain another opinion, we found out that I was to deliver a premature baby with most likely a cluster of impairments. Having no one else to trust and turn to I was back on the phone with Luba. Not only did she guide me with her kindness but also gave me some informed decisions that we as a couple could talk about. These calls were often in the evening hours when others usually called it a day. Luba was there in her office extending herself to help others!

Luba's work with the Conger family (and many others in the Binghamton community) did not end here. After the birth of our very disabled and critically ill child, she was on the phone working her connections across the country. Information was put into a Possum Program out of Vermont while our baby battled for his life and we had no idea what had caused his many complications. She was constantly checking in with the hospital staff in the NICU and also found time to check on us and update us about her contacts in the country to obtain assistance.

Upon leaving the hospital after close to two months, Luba had worked with the medical team and guided them in developing a follow up genetic plan. It was her dedication to our case that landed us with an energetic team including a neurologist and geneticist at Albert Einstein Medical Center in Philadelphia, PA. Luba realized our anguish in not having a diagnosis and at this initial point we had no idea if our very ill baby would live or die.

Luba continued to follow our case and when our child reached age two she listened further to our concerns that we still had no diagnosis. She came out to our home and facilitated a meeting with the nursing agency, therapists and medical staff involved. At this meeting she listened to all the parties who were involved with our child and then outlined an action plan we could try. As we were reaching the end of our rope to get some definite answers she suggested that our son's case could be presented at the national meetings that geneticists attend. Perplexing cases can be presented to a group of doctors to brainstorm. Luba had again taken the extra step to listen to our pleas for help and as usual had extended herself to attend a meeting at our home. I began to have hope once more that answers could be found in time. I set a time limit of 4 years to search for the name of the genetic condition that was obsessing my every waking hour.

At exactly three years of age, our son Clifford was finally given the diagnosis of Cardio-Facio-Cutaneous Syndrome. He was approximately the 25th patient in the world diagnosed at that point. Luba's concern did not end with the diagnosis. In 2000 we attended our first clinic program out in Salt Lake City, Utah for this syndrome. We had just organized as support group leaders and Luba donated $200 for us to be able to fly to Utah. We were still struggling financially, as well as emotionally, to seek out others in our same situation.

In 2001 researchers in Rome, Italy contacted us. It was our valuable DNA they needed in order to begin work on unlocking the mystery of CFC Syndrome. Luba helped me set up the same day blood draws here in the USA and then the DNA was packed and shipped out to Italy from our home. With new cautions in shipping right after September 11 our whole box of DNA was refused in Italy and returned to the United States. I panicked and immediately called Luba so she could get a doctor's letter to process this vital shipment.

Today Luba continues to encourage me with my work as President of CFC International. We promote the network of rare disorder support groups and the power of the common person in making a difference in the world. Not only does Luba listen well, she has now gone on to teach the next generation of social workers and genetic counselors to listen to families dealing with genetic conditions.

This summer, Luba was instrumental in rounding up college volunteers to help CFC International blind the medical records to expand our registry of clinical data and potential with the BioBank program. We have a wealth of medical information that is just sitting in boxes. I had spoken to her about sharing this gold mine with the medical community so they can learn more about CFC Syndrome. A proposal to access these records has now arrived from Canada.

Luba truly appreciates the power of advocacy groups and will do whatever she can to help them move forward. CFC International has begun to blaze new trails because of the true dedication that Luba has shown us. What an amazing twelve years it has been. A very difficult situation could have destroyed us but with Luba's help we obtained answers and moved on to now help others.

Brenda Conger
President CFC International