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Cooking from the Heart:
Culinary Student with Usher Syndrome Makes History

Before taking her first cooking class at the Baltimore International College (BIC), Sarah Nelinson was already given a B+ and positive feedback on a pie she baked from scratch. The pastry dish was a gift for chefs and students at the prestigious culinary school, and it symbolized her dreams for the future. More importantly, the sweet delight was a celebration of growth and success --- Sarah had defied ominous developmental and medical predictions suggested nearly two decades earlier, and had just become the first person with deaf-blindness accepted to the 35 year old college.

Sarah's mother, Joann Levy, said that her daughter's birth was an extremely difficult one, and that her infancy and childhood were marked by challenges. By six months of age Sarah was seen by a pediatric neurologist because she was not meeting typical motor milestones. According to her mother, the physician concluded that Sarah "probably had cerebral palsy, and would undoubtedly have to wear a helmet, and would never be able to feed herself." Although Sarah struggled with hypertension, strabismus, severe hearing loss, and other medical issues throughout her childhood, her mother's pride was obvious as she said, "Sarah is turning 21 soon, she has never worn a helmet in her life, and she is in college training to become a pastry chef!"

Like most individuals with Type I Usher Syndrome, Sarah was not diagnosed until she was a teenager. Her mother said Sarah was born deaf, then experienced a progressive loss of peripheral and night vision, along with motor issues such as balance challenges. This led to the diagnosis of the most common of the three types of Usher. Sarah attended the Maryland School for the Deaf as a youngster, and earned her high school diploma in 2007 from the Model Secondary School for the Deaf at Gallaudet University. For her senior project, she created a complete Italian dinner with "the only chicken Parmesan I've had in my life that you did not need a knife to cut," her mother said. "I have loved cooking since I was five years old," Sarah reminisced. "I watched alot of food network shows on television and spent time in the kitchen..."

(continued next page...)

Cooking from the Heart *(continued from p. 1)*

learning from my dad."

Joann Levy said that her ex-husband, Dr. Donald Nelinson, is an "outstanding cook" and that Sarah learned many culinary skills from her father. "I have to admit that her early dishes were quite disastrous," her mother laughed, "but I can also say that Sarah has an innate ability for color and texture. As she grew older, the two of them created all kinds of amazing dishes." Her mother added that Sarah "doesn't use a recipe. She can read a recipe, and she has followed recipes on occasion, but most of her baking is from her heart."

"My daughter is driven in great part by a creative imagination," said Donald Nelinson. "This informs her cooking and her approach to life. Trying different combinations of foods or spices drives her to create new dishes or innovate existing ones. As a person with challenges that may defeat or paralyze others, it is Sarah's beautiful capacity to dream great dreams that motivates and drives her on. Gifts come in very different forms. We need to be able to recognize the gifts in each person, and embrace them when they come our way."

Sarah said that her dream job will be "in a fancy restaurant somewhere in the United States, working as a pastry chef after graduation from BIC." Her favorite pastry to make is "Summer Berries Granache Tart. It tastes good," she said, "and berries always brighten up my day."

Since May, when Sarah began taking her first classes at BIC, her days have been brighter indeed. "My social life is great," Sarah shared. She spends free time "hanging out at the Inner Harbor with friends," and is excited about living on campus.

College life is not all play and pastries though. "I have lots of homework," Sarah said. Also, because Sarah received a cochlear implant during Fall 2007, she said that her biggest "challenge is getting used to hearing and feeling all the weird sounds in the dorms and classrooms."

Sarah said that she has great support on this journey though. The Maryland Division of Rehabilitation Services (DORS) has worked with BIC to make accommodations and meet her educational needs. For example, DORS provided a CCTV to enlarge textbook print. The organization also provided her with an Orientation and Mobility consultation at the beginning of her first semester so that she could continue being an independent traveler on campus. In addition, BIC provided Sarah with a Vibra-Call system, which vibrates and lights up to alert her to everything from a visitor at the door to a dangerous situation such as a fire in the building. Sarah also has a note taker, a peer mentor, an American Sign Language interpreter, and other supports available as she needs them.

According to Georgia Willis, BIC Director of Student Counseling, "We are delighted to have Sarah on board! This is our first student with dual sensory impairment and we're learning so much from her." Willis said that the systematic planning strategies Sarah and her family employed prior to her first semester helped smooth her transition. Sarah visited the campus for "shadow days" to get an idea of the demands she would face at BIC. She also received mobility training for the transition before moving onto campus, and enrolled during a semester when fewer students are taking their first classes. Willis said that these steps have "resulted in a very successful journey so far. Sarah is leading the way for others with sensory impairment, and who also have a passion for the culinary arts, to pursue their education."



Sarah Nelinson — cooking from the heart and fulfilling her vision of becoming a pastry chef.

Donna Riccobono, Project Coordinator for *Connections Beyond Sight and Sound* agreed that Sarah and her family inspire "both professionals and families in the deaf-blind community. This family's strength and commitment to each other has been the most impressive. In the Nelinson/Levy family, nothing is an obstacle!"

"I have received so much support from so many people and organizations," Sarah said. "I especially want to thank my parents for believing in me all these years." When Sarah was only 11 years old, her parents took her to be in the audience of food network guru, Emeril's, cooking show. Her parents took turns signing and interpreting the show for her, and after the program taping concluded, the famous chef came out to meet Sarah. Her mother remembers his words to her daughter vividly: "One day, Sarah, when you're a famous chef, I'm going to come and work for you." Get ready, Emeril! Sarah plans on graduating with a culinary degree from BIC just a few years from now. And when she does, she will be excitedly awaiting your presence and partnership in her 'fancy restaurant somewhere in the United States!'