

Living Meaningfully While Earning a Living

By Patti Murphy

You could call Joe Steffy, 25,
a classic entrepreneur –
and a class act.

Poppin' Joe's Kettle Korn, his Louisburg, Kansas-based business, has a strong regional presence. Its signature treat, a staple at spring and summer festivals, has given Joe a modest taste of fame. Retail outlets distribute it year round. Companies order it for employee and customer appreciation days. Non-profit groups sell it as a fundraiser. The corn is popped and hand-stirred into multiple flavors at Poppin' Joe's traveling booth or licensed processing plant in the basement of the Steffy home, with Joe's employees including dad Ray, a retired farmer and factory administrator, assisting with the kettle, packaging orders, paperwork and deliveries.

"It's a good product," said Shelly Scherman, who distributes it at Louisburg Cider Mill, where Joe is in regularly to conduct inventory. "It's his baby."

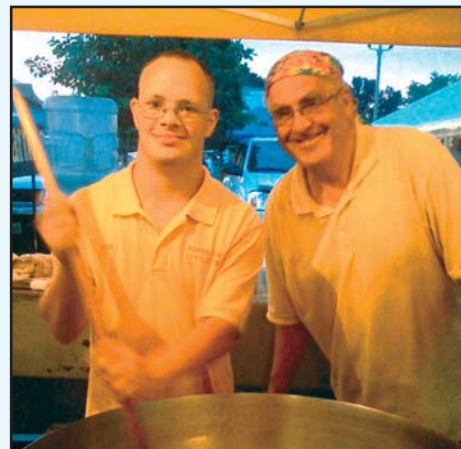
Joe lives meaningfully while earning a living. "We have always looked for opportunities for Joe to contribute," Janet, Joe's mother, said. On free time, he accepts odd jobs to help friends with heavy labor. He enjoys sports, the Blue Man Group, working with horses and playing in a hand bell choir. Joe shares his triumphs nationwide as a keynote speaker at disability advocacy events despite his intellectual and verbal limitations.

There is more to Joe's story than his autism, Down syndrome, and epilepsy. It is also about

resourcefulness, family and faith—values instilled in Joe and his four older siblings while growing up on an Iowa farm. Individuals of all abilities and backgrounds can draw inspiration from Joe's work ethic. He affirms that people with complex challenges can reach, touch and find a place in the world.

With the birth of their son Joseph Jerome in January 1986, Ray and Janet Steffy unsuspectingly set out on a journey that would redefine life as they'd come to know it. "I had never experienced anything outside what is considered normal," Janet said. Ray for the first time witnessed childbirth. He shared his wife's uncertainty upon meeting their medically fragile infant, their only child delivered via Caesarian section, and confirmation of the Down syndrome diagnosis within a few days of his arrival.

Janet, then 43, took comfort when her youngest daughter, then 17, held Joe in the hospital room and said everything would be fine. Doubt lingered and Janet rarely left the house that year. Ray and she found hope doing what they believed they had to. Joe immediately received in-home early intervention services including occupational and physical therapy. His parents learned special techniques for feeding Joe and other new necessities. The prognosis was poor. At six months, Joe regressed in response to a vaccine and experienced seizures, "sometimes hundreds on a single day," Janet said. He appeared limp and did not respond to sound or light. One-year-old Joe spent a month in treatment at Gillette Children's Specialty Healthcare, a St. Paul, Minnesota hospital. Side effects



from steroids prescribed for the seizures proved rougher than his epilepsy. After a series of outpatient visits to Gillette, Ray and Janet asked to stop the medication. The doctor objected but agreed to release Joe to the care of their local physician.

As he grew, Joe slowly responded better to his environment. The Steffys gradually learned not to take to heart discouraging comments at medical appointments, extended family gatherings and even at church regarding the bleak future awaiting their little boy. "All we knew was that Joe needed a home, and to be loved and cared for," Janet said.

At age 4 Joe was walking and physically capable of activities typical kids enjoy. Talking remained a struggle, but with help from a speech-language pathologist (SLP) at Mercy Health Center in Mason City, Iowa, he learned to sign and imitate spoken language. His parents obtained the portable augmentative and alternative communication (AAC) device the SLP recommended for Joe. They sensed that he had things to say and wanted to know him better. The device's symbol-based vocabu-

lary, concrete and categorized, aided their interactions. Joe's attraction to the technology made sense, for he similarly liked to keep his toys, clothes and daily activities in a particular order.

Some of his traits were harder to understand—the flatness in his disposition and his tendency to fixate on objects, for example. In kindergarten Joe attended a clinic for help in curbing repetitive self-injurious behaviors. Janet knew he showed characteristics of autism as indicated by the clinical report and a book she read. Joe was 12 when diagnosed with an autism spectrum disorder. The family by then had moved to Kansas, where the cards unfolded in ways that drove his uniquely fulfilling life.

Hands dealt Joe seemed unfair at times. His parents found spotty support and generally low expectations for their child at school. "There was an enormous gap between what the professionals reported and what the family experienced," Janet said.

The high school transition team seemed to know a Joe probably destined for sameness in an adult day program or sheltered workshop. But others saw a Joe who thrived on pitching in and learning tasks by watching then doing. He cleaned and vacuumed at home. Joe's oldest brother, who runs a financial services office, entrusted him with moving boxes and setting up for conferences. A stable owner who met Joe in a middle school riding program later supervised him at a job incorporated into his high school curriculum. He fed, walked and cleaned stalls for some 30 horses early most mornings, his dad serving as job coach. When plans to join a Special Olympics team did not work out for Joe, the swimming instructor worked with him one on one and later hired him for maintenance work at the community center that housed the pool.

After a particularly unsettling transition planning meeting, the Steffys decided on an unconventional path toward the future for their 14-year-old son. Ray had a coincidental "Aha!" encounter with a kettle corn vendor while vacationing in Alaska. Instinct

and industrial savvy told him Joe could master the basic steps of that business: following a simple 4-ingredient recipe; hand stirring hot oil, corn and sugar in a large kettle; seasoning the mix; dumping and separating the corn evenly on a screening table until cooled; and bagging, sealing and selling the finished product. Ray returned home ready to write a business plan. He and Janet proceeded cautiously but acted promptly on possibilities. They met Dave Hammis, senior partner with Griffin-Hammis Associates LLC, a consulting firm on customized employment for people with disabilities. The Steffys were open to the risk of helping their son launch a business, Hammis said, and kept expectations real. Joe was in the midst of a trial work period preparing and selling kettle corn for a local Wal-Mart when, with Hammis' guidance, they applied for resources available through the Kansas Council on Developmental Disabilities and Kansas Vocational Rehabilitation Services for start-up businesses. The funding covered purchase of a new kettle and booth equipment—Joe had been using used items—and a computer, printer, and 18 months' worth of raw materials for routine operation. In 2005, Poppin' Joes became a sole proprietorship. Under the Plan to Achieve Self-Support work incentive program, Joe in 2008 reached an income level where he stopped collecting Supplemental Security Income cash benefits but remained eligible for health care under Medicaid. He moved into his own home with a paid live-in caregiver.

Poppin' Joe's employees, also carefully screened by his parents, range from a teen they met at church to a middle-aged small business owner who advertised on Craigslist for a mentoring opportunity. Virtually everyone associated with Joe is a mentor, Janet said, because they work side by side, not over or under him. His siblings are preparing for a more active supporting role in the business when their parents must decrease theirs, but Joe will always be in charge. That means he can switch job tasks at will, addressing his

attention deficits and sensory needs. He could not do that easily if he worked for someone else.

Working helps minimize Joe's challenging behaviors. He keeps his AAC device handy for breaking the ice with new people and visual reminders of his tasks. It has served as his voice for speaking engagements from the Midwest to Arizona, Texas, Georgia and Washington D.C. Audience members leave inspired. Some order large shipments of kettle corn. Parents of small children with special needs send grateful emails via the Poppin' Joes website, <http://www.poppinjoes.com>. Joe composed and programmed his presentation on the device with help from a team at Schiefelbusch Speech-Language-Hearing Clinic at the University of Kansas, where he receives AAC services. His dad operates the Power Point part of the presentation from a laptop while Joe speaks. With his new device, the DynaVox Maestro, Joe can run the visual portion on his own while speaking. It provides most features of mainstream computer technology and more significantly ensures Joe a powerful voice. His engaging delivery usually ends with a thumbs-up and a smile.

"I was really taken aback because he doesn't have use of a lot of verbal language," said Roxane Romanick, board president of Designer Genes, a North Dakota-based Down Syndrome Support network hosting Joe again this spring. She likes that Joe has employees instead of job coaches, saying it's no different than executives having administrative assistants.

If there's a downside, Hammis said, it's that more folks don't know customized work situations are possible. It's sad to find that out as a 60-something after years of sheltered employment, he said, but the Steffys are raising awareness. "Joe keeps shedding light for others that this can be done." •

For information on customized employment, visit www.griffinhammis.com.

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