

# THE OPEN DOOR

PROVIDING QUALITY CARE TO DEVELOPMENTALLY DISABLED PEOPLE THROUGH COMMUNITY LIVING

After visiting Seth Canyon on a routine call, CLC Facilities Manager Nick Patchoros was so impressed by Carol's work that he submitted this story.

"I was at Seth Canyon one February afternoon and noticed the beautiful renovation work Residence Manager Carol Grant completed in the basement," says Nick.

"Over a three-month period, she cleaned out, organized, painted (with the help of consumer Tom M.) and personalized the walls with inspirational quotes and pictures of each consumer."

Carol turned an old television stand into a table by removing the legs and glass doors. In addition, she repurposed an old drum set into customized stools with upholstered seats that she crafted herself. "It was quite a transformation," says Nick.

Carol, who has worked at CLC for 13 years, commented, "I wanted to create a room for arts and crafts, exercise, and a place for our group to just relax. The wall art represents a family tree because we, Eddie, Tom, Ben, Jimmy, Frank, Ernie, Karen, Donna, Diane, D., Diane R. and Petra, feel just like a family."

When asked what else she needs to finish the room Carol had a ready answer, "A consumer's family is buying a wicker chair, so all we really need is a big screen TV!"



Carol, Tom, Karen and Eddie enjoy the new Rec Room that Carol built.



Carol gave new life to an old drum set by making coordinating cushions for extra seating. Who says you can't have both style and comfort!



## A Tale of Two Riders Jonathan Lukens

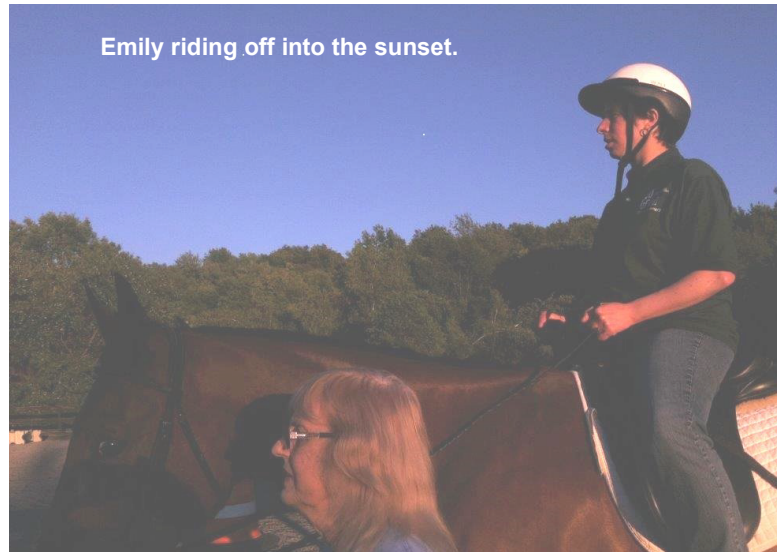
**Emily:** Picture a young women leading a group of horseback riders out through the barn doors. Suddenly the horse she is riding spooks, and sends both rider and horse flying through the air sideways several feet. The still startled horse begins to undulate up and down for several seconds causing the rider to pulsate momentarily. Several volunteers and the instructor gasp at the sight, and automatically prepare for the worst. Thankfully that moment never came.

The rider drops back into her seat and with precision deftly turns the horse in a small circle. The horse responds to the skillful rider by settling down immediately.

Two years ago if someone had told me that rider was Emily I would have shaken my head in disbelief. However this one moment in time perfectly encapsulates the remarkable growth that Emily has made over the past several years.

Anyone who knows Emily is aware of her remarkable and often bumpy journey both in the saddle and off. In both situations she has learned to embrace the lessons and skills that have been offered whether it has been writing in her journal to express her feelings, and emotions, practicing her yoga breathing or learning to post a trot.

Emily is not only an accomplished rider, she has become a skilled horse and chicken handler, gardener and fitness maven. Her well developed empathy for all members of the animal kingdom has been both inspirational and instructive towards her colleagues. She has also learned to interpret the emotions of horses and delights in sharing them freely with her peers.



**Karen:** Picture a nine year old girl with Prader-Willi Syndrome and her parents escaping from a totalitarian regime behind the Iron Curtain. They land in Kennedy Airport in a strange country where no one speaks her language. Mixed feelings of uncertainty, fear and excitement are her reality and will be so for quite some time.

How will I be treated in this new place? Will I suffer the fate of my Romanian counterparts and be sent to a state run hospital only to disappear forever.

Fast forward decades later and this young woman sits proudly on a horse. She walks and trots the horse with precision moving up and down in the saddle in perfect rhythm to the movement of the horse.

Having Prader-Willi syndrome has meant for Karen that for much of her life she has been out of rhythm with the rest of the world.

Karen is an intelligent and kind woman who's perpetual craving for food has meant that she must live in a more restrictive environment and often be relegated to sharing her day program with those far less capable than her. Even amongst her peers Karen's sensitivity has been her undoing at times.

Since coming to Winslow Karen has blossomed. Riding is not her only passion at Winslow. She is truly a renaissance women who enjoys arts and crafts, music as well as gardening, chickens and horses.

Karen's hard work and commitment to the Winslow program has been an inspiration to her Prader-Willi peers and she has become a real trail blazer.

So this is a tale of two riders. The trail sometimes has its ups and downs, perhaps even a fallen branch or two has stopped their journey forward. For these two ladies, however, I suspect the trail will be ever widening with many more green pastures ahead.



## MESSAGE

### FROM THE EXECUTIVE DIRECTOR

February 13<sup>th</sup> marked the passing of Harry Persanis, a dear friend and one of the most tenacious advocates the field of developmental disabilities has ever seen. It seems hard to believe that it was almost forty years ago that he walked into my office and introduced himself. He was looking for a program to meet the needs of people with Prader-Willi Syndrome (PWS), then an almost entirely unknown condition.

Our scheduled meeting lasted almost two hours. When Harry left, the office staff wondered what had just happened in there. It was certainly loud; that's how Harry emphasized his talking points. Sometimes it was stone serious, sometimes it was funny, and sometimes everyone laughed out loud.

Harry was determined to put a face and name on Prader-Willi Syndrome. Harry helped establish the first registry of people with PWS. He was an editor of the first newsletters and called every elected official who would answer the phone to bring his point home.

A one man referral and information service. I struggle to describe the breadth of Harry's influence, especially across New York State, but reaching to other states and even to Europe. Sometimes he would simply show up with guests from all over, both domestic and foreign. He knew how to pull people together for a common cause. I smile when I think of the times where this approach didn't work... he'd lock you in a closet until your thinking began to parallel his!

Harry's reputation grew exponentially, to the point where posters were hung at the Statewide PWS convention with his picture and a caption that read, "Need Help? Dial 1 800 CALL HARRY." At another conference he posed a question to the newly appointed Commissioner. The Commissioner responded by looking carefully at him and asked "Are you Harry Persanis?" He said "Yes I am." The Commissioner said "Ah, yes, I've been told all about you!" Everyone in the room laughed.



Harry Persanis

Harry was an effective fundraiser and the person you would always call if you wanted a broader view of what was going on. Most recently he was very concerned about how the Transformation Plan would affect services, not just for his own daughter, but for all people with disabilities. He was skeptical about the implementation of mandated managed care plans and how these would affect health care. I share his concerns; these issues are now right on our doorstep. I wish I could pick up the phone and 1800 CALL HARRY for his good counsel, sharp thinking and most of all his humor. Our prayers for comfort go out to wife Muriel, daughter Chrissy and son Matthew, as well as to his extended family.

*John Porcella*

## YOLO! RECEIVES RAVE REVIEWS!

On Friday, February 26, CLC consumers flocked to a disco dance gathering they nicknamed **YOLO!** Held at CLC main offices at Radio Circle Drive, **YOLO!** was by all accounts a great success, and already consumers are anxiously awaiting word on a future dance party. The room was decorated in glitzy disco style, and Kitchawan manager Devika served as DJ under the alias DJ Snazzy Veek! So what does **YOLO!** stand for? **You Only Live Once!** (of course!)



Joyce & Gino take a short break from the dance floor.



Abby dances up a storm!



DJ Snazzy Veek played all the current hits and classic disco.

Kate enjoyed every tune played.

**SKILLED  
CHEF**

# Meals by Michoal

**SAVVY  
CONSUMER**



Photo credit: Irene Quill

Michael started his new enterprise, *Meals by Michoal*, during the summer of 2015. What's unique about his business is that instead of people coming to him, he travels to the people. "Actually, I go to their kitchens and cook, so everything is fresh and homemade."

Michoal shops on a weekly basis for ingredients and prepares healthy, gourmet style dinners for CLC consumers at eight residences. He learned cooking basics at culinary school in Brooklyn, which he attended for just six months.

Michael, however, claims that he is truly self taught. "Most of what I know I learned by myself. I like to experiment with spices and different flavors and I've come up with some real winners; at least that's what the consumers tell me."

Some of his recipes include chicken wrapped in bacon, salmon encrusted with a Panko breadcrumb and leek blend, and Michoal's meatballs with tomato sauce. "But most everyone's all-time favorite is my meatloaf," says Michael.

"I make a traditional one with beef, pork and veal, and also one using ground turkey. Because turkey can be bland, I jazz it up with orange flavors and Japanese spices. I usually serve it with asparagus. A lot of the consumers don't like vegetables. I tell them no vegetables, no meatloaf!"

Michoal shops for ingredients at a local chain grocery store. "One of my biggest challenges is sticking to the budget," says Michoal. "I try to buy the freshest food and create delicious dinners with a unique twist. But I feel limited with the ingredients I can find."

CLC's newest chef, however, has big ideas that he hopes to implement going forward. "I would like to buy in bulk and get a wider variety of items at places like Whole Foods and other specialty markets. If you look for what's fresh and on sale, you can do just as well at these higher end places. It just takes a little more time and planning."

Armed with his creative cooking talent and an eye on the bottom line, you could say he's not only a skilled chef but a savvy consumer.

## MICHOAL'S CHICKEN WRAPPED IN BACON

Pre-heat oven to 350°F

8 pieces of boneless chicken breasts (any obvious fat removed)

24 pieces of bacon (3 pieces wrapped on each chicken breast)

Mix together 2-3 tablespoons olive oil seasoned with 1 teaspoon pepper and 1-2 tablespoons honey

Flour

2-3 eggs, whisked

Panko breadcrumbs

Dip each bacon wrapped chicken breast in the oil mixture. Then dip in flour and shake off excess and dip in eggs. Dip entire chicken breast in Panko breadcrumbs, coating both sides.

Place on parchment paper lined cooking sheet and put in oven.

Cook at 350°F for 45 minutes. Serves 8

## CLC Corp. Board of Directors

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# Advantages of a Pooled Supplemental Needs Trust

Kaitlyn Eisen, Esq.

Many individuals with persistent disabilities depend on government support in order to pay for their basic every day needs such as food, housing and medical care. However, in order to qualify for benefit programs, a person must have only limited financial resources as determined by State and Federal law.

At the same time, government benefits do not provide for many goods and services a person may need in order to enjoy a high quality of life. Moreover, individuals with disabilities are facing a period of diminishing government support. A Pooled Supplemental Needs Trust ("Pooled SNT") offers an attractive solution to this inherent dilemma.

The funds held in a Pooled SNT, such as the one managed by CLC Foundation, Inc., will not jeopardize an individual's eligibility for government benefits. The funds held in a Pooled SNT are not counted in the financial resources test for benefit programs. As a result, individuals can utilize trust funds to supplement their government benefits.

Beneficiaries of the CLC Pooled SNT utilize their funds to vacation, travel with or visit their families, obtain tickets to concerts, sporting events and even movies. Trust funds are also used to purchase appliances and home entertainment items such as a television or personal computer. Beneficiaries can also purchase necessities such as clothing or pay for medical expenses not covered by Medicaid or Medicare.

Pooled SNTs are especially attractive to families who do not have someone who is willing or able to serve as a Trustee. In such cases, a Pooled SNT is a great alternative. Pooled SNTs are managed by a non-profit organization, like CLC Foundation, Inc., which has extensive knowledge of public benefit programs and the rules pertaining to trust distributions.

For over twenty years, CLC Foundation, Inc. has managed the CLC Pooled SNT. Today the CLC Pooled SNT has over 325 members and it distributes more than three million dollars (\$3 million) annually on behalf of the beneficiaries.

Pooled SNTs also offer an alternative to reimbursing the government for the cost of medical services incurred over the course of a beneficiary's lifetime. Members of a Pooled SNT can elect that any amount remaining in the trust after a beneficiary passes away be retained to help support other individuals who suffer from disabilities or be distributed to relatives or other charities.

If you wish to learn more about the CLC Pooled SNT, please call us at (914) 241-2076 or visit our web site at [www.clcpooledtrust.org](http://www.clcpooledtrust.org).



**Ms. Eisen is Associate Executive Director of CLC Foundation, Inc.**

## HIDDEN TREASURES TALENT SHOW

Wednesday, June 15 at Fox lane High School

Art Show 6:30 pm Talent Show 7 pm Admission \$10

## CLC GALA

The 2016 CLC Gala will be held on July 24 at Greentree Country Club in New Rochelle from noon to 4pm.

## WALK THIS WAY

Deborah Jarry

Are you a perpetual couch potato? This doesn't mean you are always on the couch. It means you're not doing enough activity to be healthy. Walking is a great way to exercise and get in shape. It's convenient, low cost and you already know how!

Walking is just what Ron C. and Louise B. are doing a lot of these days since joining the Curry Street Tracker Program this past January. Every day, Ron and Louise wear wrist activity trackers that count their every step. They also exercise by walking on the treadmill daily at Curry Street and have been *stepping it up*. The trackers register even when they are at day programs, walking the track on warmer days, and even when they're just moving around the house. (Thank you, Connie, who has been a true motivator for both participants.)

Louise and Ron average 7000 - 8000 steps per day. Ron actually calls me when he goes over 10,000 steps. He reported that he's already lost some weight, and both he and Louise are very proud of their accomplishments. Results are recorded on a poster at their home. Besides feeling better, there are other incentives to the program including earning badges, meal planning with Debbie, and even getting featured in this newsletter. Food and treats are never used as reinforcement.

So if you see someone walking the halls of CLC and they have an important looking badge around their neck, try to keep up with them. If you would like to get involved, ask your residence manager. The only investment is purchasing your own activity tracker or pedometer. Happy trails!

*Deborah Jarry is a certified dietitian/nutritionist and an active member of the Academy of Nutrition and Dietetics. She is a member of the New York State Education Department Division of Professional Licensing Services. Her expertise is in special needs populations and people living with Prader Willi Syndrome.*



Ron and Louise proudly show off their tracker badges.

## GET READY TO ZUMBA!

**Hidden Treasures** held its second annual ZUMBA fundraiser event at Equinox gym in Armonk, NY on Sunday, February 21. By all accounts a smashing success, the hour long class was led by instructor extraordinaire, Lisa.

**Hidden Treasures** artists displayed their art work in the lobby, where gym members could view and purchase pieces. After the class, participants had full access to the gym and enjoyed light refreshments with their new friends.

*Denyale Werthner*

**Hidden Treasures** is an arts, music and dance education program.



## MEET ANDREA !



Andrea shows a bead art kit. "They are so much fun and not expensive at all."

The winter holidays have passed, the sky is gray and although the trees are still largely barren, tiny buds give hope that spring will be here soon. I drive up to a charming Colonial-inspired townhouse to meet with Andrea L. She's lived here since 2012, and I recall visiting this residence in the past to meet her congenial roommates Ann and Nastassija.

Andrea is unique for a CLC client as she is the only one who has a driver's license and car. She puts her Hyundai Elantra to good use to travel to her job of nine years at Goodwill in Somers. Her responsibilities include separating donations and straightening up the isles for the customers. Her schedule varies, but she can work as many as five days a week.

An occasional bowler, Andrea has a strong creative streak, and participates in *Hidden Treasure*, an arts, music and dance education program. "I'll be dancing to *Cheerleader* and *Jitterbug* in our annual Talent Show this June," she says proudly, tossing her beautiful, wavy strawberry blonde hair.

Not content to just entertain others, Andrea also likes to be entertained. "I love funny movies and I have a number of favorite TV shows. I like *Full House*, *Saved by the Bell*, *Jeopardy*, and *Wheel of Fortune*. I learn a lot from those game shows. I also watch Steve Harvey on *Family Feud*. He's hysterical. I especially like watching shows on our big, new screen TV."

Every month, Andrea travels to Carmel to see her surviving parent, Richard. She also has a brother Kevin who resides upstate in Albany. When the opportunity is available, Andrea takes a true vacation. She traveled to the end of the Garden State Parkway last year to Wildwood with its beaches and boardwalk, and Cape May, New Jersey, a beautiful Victorian town on the Atlantic Ocean. She also traveled north to gorgeous Lake George, New York, although she really prefers the warm weather and plans to go to Florida one day. With the brisk temperatures outside, we agree that's a great idea.

Although she occasionally treats herself to IHOP, Andrea also likes to cook and does so on Wednesdays and Fridays. Sometimes her friends come over for baked ziti or a special chicken dish. While dining, Andrea turns up the songs of music artist Pit Bull.

At the end of the day, Andrea finds relaxation in crafting. "I love to make bead art," she says, and quickly retrieves some creations from her room. She also displays an intricately woven friendship bracelet. "These are my favorite to make because they remind me of my good friends, Tina, Jenny, Louise, and Jackie. The best times happen with friends, you know."

D. Descloux

## Mr. and Mrs. Cherry: A Gift of Life

A unique kidney transplant, performed at Montefiore Medical Center in November of 2015, has resulted in four people gaining their health and quality of life back, including one with a strong tie to CLC, Rebecca Cherry, wife of CLC employee Lawrence.

It began with the generosity of 30-year-old Army veteran Christopher Forthman, who volunteered to be a kidney donor. This decision ultimately affected the lives of four Bronx patients in need of a donated kidney.

Lawrence wanted to donate his kidney to his wife, but was incompatible with her. A team from Montefiore including surgeons, nephrologists, nurses, transplant coordinators, social workers and nutritionists, evaluated patients in need of kidneys and concluded that four families had matching blood types and similar antibodies to those in the other families. Then the real work began and ultimately four people received healthy kidneys, including Rebecca.

Today, Lawrence reports that all are well. "We check in at Montefiore regularly and are doing just fine," he says happily. "We were all given the gift of life, and for this we are truly grateful."



Rebecca and Lawrence Cherry

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