

# ACCESS news

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Independent Living  
of the Genesee Region  
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Batavia, NY 14020  
(585) 815-8501 (Voice/TDD)  
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## On the Move

*by Rae Frank, Director*

This Spring you will find Independent Living of the Genesee Region in new locations. Thanks to the Western New York Independent Living, Inc. Board of Directors and Douglas J. Usiak, Chief Executive Officer, the Batavia office was able to relocate to newly constructed office space in the Crickler Building located at 319 W. Main Street. Our new space provides double the square footage of our former office and allows us room to grow. Over the past several years the Independent Living Center has tripled in staff and programming. New partnerships and funding opportunities have supported the expansion of our peer led organization. The newly dedicated Douglas J. Usiak Multipurpose Room can seat up to 40 people and is available to other community organizations for their use.

In Wyoming County we have relocated to 2407 Main Street in Warsaw, right across from Tops. This centrally located office will allow people to stop in without an appointment and get to know the services we provide. This office is just down the hill from the Grandview Terrace Apartments which are set to open this Spring. Please join us for an Open House and Ribbon Cutting Ceremony in Warsaw on May 22nd at noon.

Many people are not aware of all the services and programs we provide. Throughout this newsletter you can read about what we do and hear from our team members.



## **Spotlight on a Leader: Erycka Lea Kosinski, ILGR Council Member**

It was just a few years ago that someone referred Erycka Lea Kosinski to Independent Living of the Genesee Region (ILGR). Previously, while trained as a Licensed Practical Nurse, and planning to go on to study sociology, Erycka had a traumatic event that led to bouts of anxiety and depression, ultimately being diagnosed with Bi-polar Disorder (formerly called manic-depressive illness), and Attention-Deficit/Hyperactivity Disorder (ADHD). Fearing that all her dreams had been extinguished at age 20, she was unable to continue working. Once her husband was, himself, unable to work due to an injury, even with her qualifying for Social Security Disability Insurance (SSDI), her family had financial difficulties and she could not afford traditional counseling when she needed it.

However, then she learned that almost all services of ILGR, (except van transportation for those outside certain qualifying programs), were provided at no cost to the individual. Erycka availed herself of a variety of the regular Independent Living services, plus others such as Anger Management Classes, and it turned her life around.

The Agency even helped her husband to acquire health insurance. They have encouraged her efforts to make her German Shepherd-Chow mix, Akira Rose, an Americans with Disabilities Act federally-certified service animal for helping with her anxiety.

Erycka became one of ILGR's most enthusiastic volunteers, working on the ILGR table at the Genesee County Fair; for the "Taste of Independence" food sampling extravaganza; and at other fundraising activities. A self-proclaimed good-will ambassador for IL, she carries cards and literature with her everywhere. All this involvement got her noticed, and she was invited to the ILGR Council, to help set direction and policy for the Agency.

Noticing how much the ILGR services have grown in recent years, Erycka has some ideas she would like to see become a reality: a structured program to help volunteers appreciate the uniqueness of IL's consumer-first philosophy within social service agencies; to recruit more "feet on the ground" to dispel the notion some have that we are an authoritarian organization; more active outreach to the community to promote involvement with, and awareness of the considerable capabilities of, citizens with disabilities. She feels it's particularly important to bring this message to the schools, to reach the next generation of leaders, and, through them, to their parents. ("Say, Dad, doesn't that sign mean that only people with disabilities can park here?")

*continued on page 3*

People need to expand their concept of Independent Living to understand that everybody has a right to gain independence; just as everyone can have their own IL story: consumers, volunteers, staff, and Council Members! As she describes it, “Anybody’s building blocks can be knocked down in their life – but they can be put back together, perhaps in a new, better way, if you have help with the ‘3 E’s: Education, Empowerment and Equality’”.

Lead on, Erycka!

## **What is Health Homes?**

*By Ariana Hiscutt*

Health Homes programs can be defined as coordination of care for individuals who have the following: chronic conditions, mental health illness and substance abuse disorders. This program has been created in conjunction with Medicaid, to assist their members. Having Medicaid is one of the qualifying factors of this program. ILGR works with HHUNY (Health Homes of Upstate NY) and covers 2 of the 22 Counties HHUNY serves (Genesee and Orleans). Health Homes Care Coordinators utilize a clinical approach and takes focus on a team-based care plan. Coordination includes the consumer, providers and family members to assist making their life as healthy as possible and to remain a support system to achieve their health goals. In order to qualify

for the program, one must be diagnosed with one of the conditions listed above. Examples of diagnoses are but not limited to: Diabetes, Asthma, Multiple Sclerosis, Depression, Schizophrenia and many more. In order to enroll an individual in this program, a community referral must be sent to HHUNY or a care coordinator can meet with the individual and complete a referral together. Support throughout the health field is crucial to an individual dealing with certain diagnoses alone. Health Homes can be beneficial for many, but it is not a well-known program. NYS has attempted to make providers aware to refer individuals to assist with these needs, which has resulted in the program growing, but has not quite reached its full potential yet.

## **Overcoming the Odds**

*By Amie Dedman*

I recently did my first PCA orientation for someone who is blind. This woman wants to take care of a friend. They have worked together to come up with a routine that works for them and their other Personal Care Aids. In doing so, this has kept them in their home and independent. To be given this opportunity has made her feel wonderful, since she was unable to do this in the past for other agencies. What is so amazing is that she is an active consumer in the CDPAS program and has a PCA herself.

## **An Impact on Someone's Life**

*By Cathy DeMare*

When we were still in our old location, we had a consumer come in to see an ILS. While waiting for her appointment, we were chit chatting about Christmas coming up soon. She was telling me how it would be the first Christmas in years that she was able to spend with her son. He had addiction issues and had been in and out of jail but was finally clean. We just talked back and forth about how we both had family members that had been affected by addiction and how it is hard on everyone involved, etc.

She came back the following week for another appointment and as she was leaving, she stopped and said, "You probably don't remember me, but we spoke last week about my son." At first, I did not remember until she mentioned her son. She said, "I wanted to let you know that you really helped me. I didn't know how much I needed to talk about him and everything that had gone on. I was stressed out about seeing him and didn't even realize it until we spoke. I left here feeling like a weight had been lifted."

To me we were just having a conversation to pass the time but to her it was more. The thing is, you never know how what you think is a casual contact with someone can really make an impact on their lives.

## **Code Blue**

*By Dai Nguyen*

On January 5, 2016, Governor Cuomo signed an Executive Order to protect homeless from inclement winter weather, known as the Code Blue Law. The order will ensure that homeless individuals are directed to warmer places during the inclement winter weather, which can cause hypothermia, serious injury and death. Last month, Lawrence Bierl, a well-known homeless man in Erie County, was found dead in a bus shelter on Main Street in Williamsville, NY during the code blue condition, which is when the outdoor temperature is 32 degrees or below. His death left more questions than answers and attracted a great deal of public notice. One of my duties is promoting the Executive Order to the public, especially to Genesee, Orleans, and Wyoming Counties to avoid tragedies like the death of Lawrence Bierl. Recently, I successfully cooperated with 2-1-1 Western New York to establish a Text Notification, which residents, who opted in the Text Notification, would receive a text message informing that the Code Blue condition is called and instructions of where they can go to get help.

## **Lunch in the Dark**

*By David Dodge*

Three years ago, Independent Living of the Genesee Region (ILGR) embarked on a unique adventure we named Lunch in the Dark. The goal of this event is to educate the community on making events and programs more accessible to people with disabilities via a disability simulation. The simulation has participants experience lunch in a darkened environment wearing blindfolds. When the event first started, ILGR began an excellent collaboration with the New York State School for the Blind (NYSSB), which will now be hosting the event for the fourth year in a row in their gymnasium. The NYSSB has provided us with not only the space to have this event but also with staff acting as sighted guides for participants going through our buffet line. In addition, the school has a wealth of knowledge on blindness and visual impairment including several devices showcased at a table for people to take a look at after the formal event is finished.

Feedback on this event has been very gratifying including one participant saying, “this was one of the best trainings I have ever attended” and participants tend to encourage family members, friends, and colleagues to attend after they have experienced the simulation. Last year, a representative from the New York State Commission for the Blind (NYSCB) joined our

lunch with a presentation regarding the agency’s services and held a table after the event for individuals wishing to learn more. This year, NYSCB will be back with us for their presentation and table but will also have more staff present to help us guide participants through the simulation. In addition, we are thrilled to have a new caterer this year, Genesee Valley Education Partnership Culinary Class will be making our menu of tossed salad, roasted chicken, seasonal vegetables, risotto cakes, pasta with red sauce, and dessert. We have also decided to open this year’s event up to corporate sponsorship and would like to thank Council Opticians of Batavia for sponsoring our event. If you are reading this and are interested in becoming a sponsor it is not too late! It has been an amazing experience watching this event grow over the years and to be able to put it on for the community for the fourth year in a row.

### **Lunch in the Dark**

Thursday, April 25, 2019

12:00 p.m. — 1:30 p.m.

NYS School for the Blind

Gymnasium

2A Richmond Ave.

Batavia, NY 14020

Cost \$15/person

RSVP Donna Becker

585-815-8501 x411

## **We Did Survive**

*By Debra McKnight*

Della came to work at Independent Living in the Summer of 2015. If you ask Della what her favorite part of her job is, she will answer with a big smile “helping people” period. Independent Living is an organization that assist people with disabilities.

Della clearly understands what it means to have disabilities. Della has had her share of life turnabouts. Della started off at age 7 being molested by family members; she became a drinker at age 9; pregnant at 12 years old; baby dies at 15 months old; mother dies when Della was 14 years old. From there, went to prison at age 19, was released when she was 32. Della became a drug addict at age 40. This cycle went on until she was 46.

Mental Health, Mental Health, Mental Health, Mental Health, Mental Health, Mental Health, Mental Health. Can anyone hear me? Yes, Della heard those words thrown around as she went from jails to other institutions such as the state hospitals. Della’s culture of African American did not adhere to the word mental health or psychiatrist. This meant you were “crazy”, so Della went through life on her own trying to deal with whatever life threw at her.

At age 52, Della went back to school, to earn a degree in Human Services. Della was the first in her family to earn

a college degree. While in school, Della was an intern at Independent Living, which lead to a professional position as an IL Specialist. While working for Independent Living, Della encountered a lot of people with issues such as what she endured. Chronic depression, PTSD, anxiety, personality disorder, anti-socialization, etc. Most importantly, it was at Independent Living that Della found out it was okay to seek out mental health. This didn’t mean she was “crazy”, it only meant you have the freedom, the empowerment, the INDEPENDENCE to have your voice heard, to shout “yes” I been through hell and back; but I am not the only one, I am not alone.

Della states that Independent Living gave her tools that eventually broadened her horizon to be a vehicle to individuals that never knew that it was okay to admit that they had mental issues, chronic depression, drug problems, alcohol problems, socialization problems. With all of this, I mean all of this, each of these people could still live independently, work in an environment with “normal” people, go to the same stores without worrying about being stared at. Because of the skilled staff at Independent Living, we can now change the saying that states “we will survive” to “WE DID SURVIVE”, with dignity and humility!

## **Thank You Knights of Columbus**

*By Donna Becker*

In December 2018, Our Lady of Batavia Council 11728 Knights of Columbus donated two knee scooters to Independent Living of the Genesee Region. One of the services that Independent Living offers is a loan of medical equipment such as canes, shower chairs, rollators, wheel chairs or knee scooters to clients for use during their recovery from an injury or surgery. The Knights donated 2 wheelchairs a few years ago and when they reached out to me again asking what our current needs were, I immediately said knee scooters! The Knights of Columbus is an international fraternal organization of Catholic men, whose first principal is charity. Our Lady of Batavia is a local Knight's Council active in making a difference in Genesee County and the surrounding area. Representing the Knights at the scooter donation were (l to r) Mike Jackson, Bernie Hoerbelt, and Bill Bogan. Representing Independent Living were (l-r) Rae Frank and Donna Becker.

Donations such as this is what makes our Loan Closet the 'go to place' in our area for medical equipment.

## **Success within the Process**

*By Dominique Johnson*

I haven't been working with this consumer very long but since our first meeting, she has expressed her gratitude for me simply listening to her without judging. The consumer expressed that everyone she has worked with in the past has either been judgmental or given her the impression that due to her past, she is hopeless. The consumer has felt comfortable enough to open up about her past struggles and her continued progression.

Even though I have only had a few appointments with this consumer, I am assisting her in reengaging with mental health and finding housing. This is a major accomplishment as she stated she hadn't trusted another for a long time after so many failures.



## **Growth in Orleans County**

*By Jennifer Pritchard*

What is new and exciting in the life of an Independent Living Specialist at ILGR? Well, we are growing our Orleans County area. We have increased the amount of consumers we see in Orleans County. I work with a housing specialist through Orleans Department of Social Services trying to assist homeless consumers with housing. Every two weeks the homeless consumers meet with us and we go over their progress. During the other weeks we are filling out housing applications and mailing or dropping them off for the consumers. We hope one day we will be able to open an office in Orleans County.

## **Support for People with Disabilities in Wyoming County**

*By Jennifer Williams*

I have a consumer in Wyoming County that was in a motor vehicle accident when she was twenty years old. She suffered a broken neck, leaving her paralyzed from the neck down. She is now in her 50's. Her mother was her main caregiver for the last thirty years but unfortunately, she passed away on November 17, 2018. I identified that a barrier for this consumer to live independently in the community is her complicated grief. Her and her family were completely dependent on the matriarch. They were really struggling.

I called Wyoming County Mental Health to inquire if there were any grief counselors that would do home visits as it is difficult for this consumer to travel due to her disability. I was referred to Spectrum Services in Warsaw. They do make home visits and they do have grief counselors. We do have plenty of supportive services in Wyoming County for our consumers.

## **Consumer Directed Personal Assistance Services Facing Major Changes Due to Proposed Legislation**

*By Patricia McAllister*

Governor Cuomo is considering major changes to the Consumer Directed Personal Assistance Program as we now know it. Consumer choice as to what agency you would like to work with may be a thing of the past. The ability to work with a local agency who can provide a well-rounded offering of services could be history. There is proposed legislation which could change the program operation to be offered through a limited number of fiscal intermediaries; and may eventually be a state operated system. Payments to fiscal intermediaries would change in a way that eliminate many agencies from being able to "afford" offering the program all together.

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The entire future of Consumer Directed Assistant Services could be in jeopardy; the only source of personalized care where a person can remain at home while choosing their own Aide and directing their own services.

If you want to be part of the solution, please consider letting your local representatives know how important the Consumer Directed Personal Assistant program is in keeping you or your family members at home, not in a nursing home. Explain how it means so much to be able to select someone you know and trust to care for you or your loved one.

Just call Independent Living of the Genesee Region (585-815-8501 ext. 400) if you need help finding phone numbers for your representatives, we'd be glad to help!

## **Just a Call Away**

*By Scott Dorchak*

Quite frequently, I find myself receiving many different calls about issues that individuals are having with Medicaid. One particular consumer called me and began to tell me about his situation. He lives alone and is certified disabled. His income puts him over the limits for Medicaid. If he was married, I would have been able to help him with spousal impoverishment protections. Being single, I would not be able to apply this for him. I then suggested that he find a job. If he could work at least just one

hour then he would be eligible under much higher guidelines. He said thank you and we ended the call.

About a month and a half goes by and I receive a call from this same consumer. He told me that he found a job working from home. I was delighted that he took my advice! I was able to enroll this individual in Medicaid under the Medicaid Buy-In Program for Working People with Disabilities. This consumer is now able to get the help that he needs and he is able to do it affordably. It is rewarding to see a consumer take initiative and reach the goals that they set for themselves.

## **Assistance from the Taste of Independence**

*By Nicole Tedesco*

A consumer of mine suffers from Seasonal Affective Disorder (SAD) which is a type of depression that occurs in the fall and winter months. Finding a way to assist her in functioning at a level that she felt comfortable, due to her mood and behavior change with the seasons, has been a struggle. As a Care Coordinator, I was able to work in conjunction with her mental health therapist to find a solution that fit best for our consumer. A light box, which is a method of treatment that assists with this condition by treating the seasonal affective disorder (SAD) and certain other conditions by exposing the individual to artificial light. Once brought

*continued on page 10*

up to the consumer, she was interested in this method but was afraid that she would not be able to afford it on her own. Through our Taste of Independence Event, we were able to utilize some of those funds to successfully obtain a light box for her. We are currently waiting for it to be shipped so she can enjoy her day to day living without a struggle.



## You are cordially invited to our Open House

**Wednesday, May 22**

**12:00 p.m. — 2:00 p.m.**

**Ribbon Cutting 12:00 p.m.**

Join Independent Living and  
Becky Ryan, Town of Warsaw Supervisor  
for the Ribbon Cutting.

Come check out our new office located at:  
**2407 N. Main St., Warsaw, NY 14569**

Some of the Services we offer:

- Consumer Directed Personal Care Assistant Services — Medicaid consumers may be eligible for in-home personal assistance.
- Loan Closet — Free durable medical equipment such as walkers, wheelchairs, canes, shower chairs for loan.

- Medicaid Application Assistance — Our staff will help you apply for Medicaid with the right qualifications.
- Support and Wellness Classes — Anger Management, Declutter, Grief & Loss, Chronic Disease, Diabetes Self Management Programs.
- Information and Assistance with Employment, Housing Search, Budgeting. Bring an advocate with you to Dept. of Social Services or Social Security meetings.

## Programs & Services

Advocacy for Individuals  
Advocacy for System Change  
Aged, Blind & Disabled Medicaid  
Application Assistance Program  
ARTiculations Exhibition  
CDPAS Program (Member Directed  
Personal Assistant Services)  
Benefits Advisement  
Budgeting  
Educational Coaching  
Housing  
Information & Referral  
Job Search  
Life Skills  
Loan Closet  
Music for the Ages  
Peer Counseling  
Ticket to Work  
Transition Services for Youth & Seniors  
Transportation Services

*Please see our website for details:*

[www.wnyil.org/Independent-Living-of-the-Genesee-Region/Programs-Services](http://www.wnyil.org/Independent-Living-of-the-Genesee-Region/Programs-Services)

# A Taste of

# Independence



**Save the Date:**

*Tuesday,*

*September 17, 2019*

*5:30 p.m. - 8:00 p.m.*

*Ascension*

*Parish Hall*

*19 Sumner St.*

*Batavia, NY 14020*

Independent Living of the Genesee Region

Free!

# Annual Consumer ADA Picnic

Independent Living of the Genesee Region invites you to join our family of agencies to celebrate the Americans with Disabilities Act Annual Picnic. Free food, fun, and games will be provided. We look forward to having you celebrate with us!

Friday, July 26, 2019

Town of Batavia Kiwanis Park  
3808 W. Main St., Batavia, NY 14020

4:00 p.m. - 6:00 p.m.

If you plan to attend, please R.S.V.P. to  
Donna Becker  
(585) 815-8501 ext. 411

Transportation to this event may be available. Please inquire with Donna Becker.



# UPCOMING EVENTS

## **MHPC 11th Annual Policymaker's Breakfast**

Friday, April 26, 2019

## **6th Annual Night for Independence Gala**

Saturday, May 4, 2019

## **Disability Pride Parade and Festival**

Saturday, July 27, 2019

## **14th Annual Bass Fishing Derby**

Sunday, August 4, 2019

For more information contact

Marykate Waringa at 716-836-0822, ext. 146 or [mwaringa@wnyil.org](mailto:mwaringa@wnyil.org)



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no matter what difference we may have.*

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learn more at: [www.EmbraceTheDifference.org](http://www.EmbraceTheDifference.org)

# LUNCH in the DARK

**Thursday, April 25, 2019**  
**12:00 - 1:30 p.m.**

- Tossed Salad • Roasted Chicken • Seasonal Vegetable •
- Risoto Cakes • Pasta with Red Sauce • Dessert •
- *Catered by Genesee Valley Education Partnership Culinary Class* •

Participants will experience lunch in a darkened environment in order to better understand eating and socializing with vision loss. As a group, we will talk about the best practices for making events with food more accessible, as well as strategies for eating with vision loss.

**Location:**

NYS School for the Blind  
Gymnasium  
2A Richmond Ave.  
Batavia, NY 14020

**Cost to attend:** \$15/person

**RSVP:** Donna Becker 585-815-8501 x 411



*Thank you to our Night for Independence Gala Sponsors!*



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*Wegmans*

The complex block features a central graphic of a heart shape composed of various food items and community-related icons, with the Wegmans logo in the center. To the right of this graphic is a short paragraph of text. At the bottom of the block is a purple banner with the Wegmans logo in white script.

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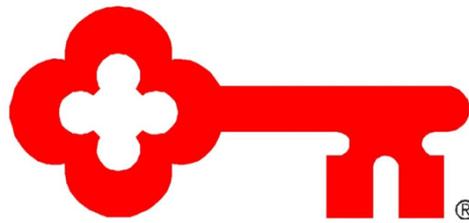
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# KeyBank



**HealthWorks**  
WESTERN NEW YORK

*Healthy employee. Healthy bottom line.*

6th  
Annual

# A Night for Independence

# Gala

*To benefit Independence Express Transportation*

**Saturday, May 4, 2019**

**5:00 p.m. — 9:00 p.m.**

**Events at the Wurlitzer**

**908 Niagara Falls Blvd., North Tonawanda, NY 14120**

**\$75.00 per Ticket • \$125.00 for Two (2) • \$500 Table of Eight (8)**

*(Basket, premium auction, and live auction separate costs)*

🌀 High end live & basket items 🌀

🌀 Music & entertainment 🌀

🌀 Sit-down dinner & a night of fun 🌀

For more information and to RSVP by April 26, 2019

Phone: Marykate Waringa 716-836-0822 ext. 146 or email: [mwaringa@wnyil.org](mailto:mwaringa@wnyil.org)

**Inclusion, Awareness, Visibility**



# Disability

# Pride

# Parade & Festival

**FREE!**

## **Saturday, July 27, 2019**

## **Canalside**

### **Parade 10:30 a.m.**

Parade route will be released shortly

### **Festival 11:00 a.m. - 2:00 p.m.**

Live performances, food, vendors, giveaways and activities

Dozens of Western New York organizations invite you to join us to celebrate the Americans with Disabilities Act and Disability Pride with food, fun, and games.

We look forward to having you celebrate with us!

For more information contact Marykate Waringa at  
716-836-0822 ext. 146 or [mwaringa@wnyil.org](mailto:mwaringa@wnyil.org)