

The Arc of Warren County Fall 2021 Newsletter



Letter from the CEO of The Arc of Warren County, John Whitehead

Camp Warren completed five successful weeks of camp despite many barriers including strict Covid-19 regulations and a staffing crisis this summer. This required Recreation Director Marci Gubich and Assistant Recreation Director Robyn Gardella to be very determined and adaptable. Staff from various other programs, including administrative staff, stepped in to assist where needed.

Was it easy? No. Was it worth it? Absolutely! About 100 people, both children and adults, got the camping experience that they desired, despite the challenges that were present.

While the past eighteen months have been unique in many ways, we have been able to adapt because The Arc of Warren County is all about overcoming challenges. Since 1954, this organization has been helping individuals and families overcome the challenges that those with intellectual and developmental disabilities face every day. It started with a group of determined parents getting together on behalf of their children and has

grown into a strong Agency that strives to serve and advocate for hundreds of people every year.

Every department has had to adjust because of the pandemic, and frankly, everyone has had to work harder than ever. However, this crisis has brought out the best in many of our employees, and this makes me very proud to be part of such an organization. You see, a lot of us are very stubborn and don't surrender easily when things don't go our way. If we are told "that's the best you can do," we try to do better. If we are told "it's never going to work," we are determined to find a way. If we are told to "give up," then we'll just try harder. If anyone tells us, "you can't," then we will do everything in our power to show that we can!

So, it seems to me that we at The Arc of Warren County today have a lot in common with our founding members and those we serve. We will continue to improve our services and achieve our mission no matter what barriers are in our way.



CEO of The Arc of Warren County
John Whitehead

Note from the Director of Public Relations & Fundraising, Annamaria Lalevee

The Arc of Warren County is an organization that helps people. Just look at our mission, which reads as follows:

“The Arc of Warren County helps people with intellectual and other developmental disabilities live a good life. We assist families to solve challenges associated with the lifelong care of their family members. As an advocacy organization, we create the kind of universal environment where the people we serve are accepted and respected in the community. Come achieve with us.”

It is an honor to work for this organization and feel that the work that each person does make a positive impact on the individuals whom we serve and their families.

Recent months have been extremely brisk with activity. Radiothon was an astounding success and we were so

fortunate to work with co-chairs Norman Worth and Jim Travis once again. They both have agreed to co-chair Radiothon for 2022 and the 32nd Radiothon with WRNJ will take place on June 8, 2022.

We held back-to-back events in July with our Triathlon with DASH Multisport and our 3rd Annual Food Truck Fest at Donaldson Farms. This fall we held a Golf Classic at Hawk Pointe Golf Club with The House of the Good Shepherd. I want to also give a special thank you to Norman Worth and Leslie Schott for all of the help and commitment to this event.

This summer I was chosen to receive the coveted Paul Harris Award from the Hackettstown Rotary Club. It was such an honor to be recognized in this manner from my fellow Rotarians. It is the highest accomplishment that one can receive from Rotary International and I am so humbled to be selected for



Director of Public Relations
Annamaria Lalevee

the year 2021.

Please know that I am constantly looking to collaborate with other organizations on projects and opportunities and am always available to talk. I can be reached at (908) 223-0884.

Early Intervention Parent – Amanda Gransky Talks about Her Experiences

Amanda Gransky has been utilizing the Early Intervention program since June 2020 for her daughter Madison.



“The experience has been amazing,” says Amanda. “Madison, who was diagnosed with Cerebral Palsy, has progressed by leaps and bounds.”

Madison receives in-person services for Occupational Therapy and Physical Therapy. As a result, she is much more mobile than she was in the beginning of the process and is working on walking.

“I am very thankful for my daughter’s

progression and for the excellent care that she has received from her therapists,” says Amanda. “When we moved from Hawaii to Belvidere a year and a half ago, I immediately reached out to The Arc of Warren County for support and she has been in good hands ever since.”

If you are experiencing developmental delays with your child between birth and three years old, please call 888.653.4463.

An Arc of Warren County Employee Highlight --- Andrew Cuenco

It was a family tradition to work at The Arc of Warren County for Andrew Cuenco. His mother was a manager for many years and retired recently. According to Andrew, he always had a gravitational pull toward the population that The Arc serves. In 2007, Andrew served as a DSP at the Asbury Group Home and is now a Relief Manager.

“It is no secret that this isn’t the most lucrative profession,” says Andrew. “Making people’s lives better as a result of my commitment provides me with rewards.”

For Andrew, he is motivated by helping the residents learn new skills and grow in their ability to make decisions for themselves. He feels more so this way with consumers who are non-verbal.



Andrew Cuenco

“Seeing the smiles on their faces and how gracious they are provides me with much fulfillment,” says Andrew.

During the lockdown, Arc employees had to get creative in their homes on how to engage consumers in a safe manner. Some of the activities that helped get everyone through this time included engaging consumers in yard games, wiffle ball, volleyball, arts and crafts, spending time on the patio and engaging in puzzles and workbooks.

“Some of our staff do 12 to 14 hour shifts and there needs to be enough to do to keep our consumers involved,” says Andrew.

When asked what suggestions he might have for new employees who work with consumers, Andrew says that it is important to have patience, human empathy and have a resilient mindset.

Andrew says that he always urges his staff and new managers to “just remember why we are here.”

“I always stress to my team that it is easy to get caught up with your own lives, but this position requires the best of us,” says Andrew. “I tell new managers sometimes you are not walking into ideal scenarios. It is important to not come to work stressed. Leave your own personal issues at the door. Rely on each other. Everyone has the same goal.”

If you are not open to being a problem solver, this career will be even more challenging for you, according to Andrew.

“We are our consumers’ families,” says Andrew. “They depend on us every day.”

After seven years as a manager, Andrew finds it to be essential to establish a rapport with new employees. It is important to support staff, especially when they go through their own ups and downs in life.

Andrew credits his mother for encouraging him to get into this field and says that his own manager – Eleanor Nero – showed him how being kind and being firm could be done with grace. His supervisor, Kayla Conklin, has supported his tenure as the manager and his philosophy on how a manager should support their staff. His fiancée, The Arc of Warren County Nursing Supervisor Kim Southard, helps keep him focused and motivated, and has supported him through the ups and downs of working through a pandemic.

“My staff at the Asbury group home deserve to be credited for their resiliency and hard work through this pandemic and beyond,” says Andrew. “They are amazing and I am so fortunate to work with them. They are Paul Kaspereen, Relief Manager (now Program Manager), Chris Bauknight, Senior DSP and DSPs Derrick Thompson, Cyle Connors, as well as Overnight Awake DSP Cameron Martin.”

Thank you, Andrew, for sharing your story!

In Remembrance of Gail Geene

Part of this article was created based on information from her sister, Jill Notte, who wrote her words of remembrance for Gail's funeral service. Jill remains very active as part of The Arc of Warren County community.

Gail Frances Geene, a 25-year resident of The Arc of Warren County's Hampton Terrace Group Home, passed away on June 15, 2021. Gail was an integral part of The Arc family and left a positive impact on those who had the honor of knowing her.

Gail was born with a rare genetic disorder called Prader-Willi Syndrome (PWS), named for Swiss doctors, Andrea Prader and Heinrich Willi, who first described it in 1956. PWS is caused by a deletion in the 15th chromosome and is characterized by learning disabilities, an insatiable appetite, weak muscle tone, and a slow metabolism. Without interventions, the combination leads to rapid weight gain.

According to Gail's sister Jill, if anyone were up to the challenge of raising a special needs child, it was their mother. She faced all of Gail's developmental delays with patience and determination. She assured doubting family members that Gail just needed extra time to walk - which she did at age 3!

Gail's learning disabilities became apparent when she started school. She repeated kindergarten, then repeated first grade before she was assigned to special-needs classes.



Gail Geene (pictured right) and her housemates and Arc staff, Lisa Wilmott (far left) and Shana Frondorf (second from right).

Gail was blessed to have several teachers in her early education that spent extra time to teach her to read. This made a huge difference in her life, as she loved books and going to the library at every stage of her life.

Today, babies born with PWS can be diagnosed within weeks with DNA testing, according to Jill; but Gail didn't receive a proper medical diagnosis until she was 18, when the rare disorder had finally made it into US medical books and was highlighted by their grandmother's general practitioner in the late 1970s. By this point, Gail had developed diabetes as a result of her extreme weight gain.

After Gail's diagnosis, their parents joined a local support group, met other parents of children with PWS, and eventually got her enrolled in a specialized program at The Children's Institute in Pittsburgh. This program

helped Gail lose weight and helped her parents continue the journey through special food preparation and other interventions. But Gail and Jill's parents wanted to ensure that Gail's future was secure as they approached their late 70s.

"They learned that a new group home known as "Hampton Terrace" had been established by The Arc of Warren County," says Jill. "It was in Phillipsburg, about an hour from their home, and it was specifically developed to meet the needs of PWS women. It took some time, but a room opened up and Gail was approved to take it."

Gail continued to lose weight at Hampton Terrace and eventually reached her goal weight after losing a total of more than 100 pounds. She reversed her diabetes and eliminated the need for insulin injections. She was

Cont... In Remembrance of Gail Geene

able to do her favorite activities with much more ease, including walking, biking, bowling, swimming, and dancing.

Jill credits The Arc of Warren County for the impeccable care that her sister received.

"I consider the direct care staff and behaviorists in the program to be some of the top experts in the world in understanding people with PWS and how to help them be happy, healthy and successful," says Jill. "They are constantly evaluating solutions, partnering with researchers at the Vanderbilt-Kennedy Center in Nashville and learning from hands-on experience, 24/7. In fact, Gail, her housemates and The Arc staff had a couple of fun and productive trips to Vanderbilt to participate in a research study."

According to Jill, The Arc community was Gail's family.

"They knew her and cared for her like she was their sister or mother," says Jill. "She was even Grandma Gail to the staff's young children and she was often invited to their homes to visit with their dogs. They traveled with Gail to bring her to our family weddings, showers and funerals. They helped me plan Gail's surprise 60th birthday party and showed up in big numbers to make the party a blast. As her mobility declined, they remodeled the house to accommodate her needs so that she could live there as long as possible. Gail and my whole family have been blessed beyond measure to have The Arc in our lives."

Shana Frondorf, Board Certified Behavior Analyst of The Arc of Warren County, recalls many of her favorite memories with Gail. One of them includes their road trip eight years ago to The Children's Institute in Pittsburgh. They had a lot of fun singing to different songs during that car ride.

"This is a moment that will forever be with me," says Shana.

Shana was also with Gail on a trip to Point Pleasant to enjoy the beach, walk the boardwalk and visit the aquarium.

"She was so happy," says Shana. "I recall her squealing with glee when she experienced the touch tanks. It was pure joy."

Shana also fondly remembers attending her 60th birthday and how pleased Gail's family was to learn that Shana's sons referred to her as "Grandma Gail."

"She beat the odds," says Shana. "She outlived the life expectancy for someone who has PWS."

Elizabeth Roof, Senior Research Specialist and Research Lab Director from Prader-Willi Syndrome Initiatives at Vanderbilt University also shared her sentiments on their Facebook page after Gail's passing:

"It makes me feel so lucky to have known her. Her participation in our studies over the years has highlighted aging in PWS and helped develop drugs that will help others with PWS. Her life had great meaning

for those who knew her and for those with PWS who will benefit from her efforts and sacrifice. I hope that she is happy, full and has a house full of puppies nipping at her heels and a handsome boyfriend who is feeding her all the food she loves. Gail, you are one in a million. Gail, rest in the peace you so richly deserve."

Gail's last 14 months here were full of challenges and uncertainty. She suffered a heart attack, a blood clot, two strokes, and seizure activity. She was in and out of six different hospitals and rehabilitation centers; yet she took it in stride and cherished the times in between when she was able to get back home to Hampton Terrace with the roommates and staff she loved. She finished her days on earth as a beloved patient at The House of the Good Shepherd and Ennoble Hospice Care.

Though Gail is not here in body, she will always live in the hearts of everyone who had the fortune of making her acquaintance.



Shana Frondorf and Gail Geene on a road trip to the Children's Institute in Pittsburgh.

Summer Time is Busy Time at The Arc of Warren County: The Chapter Runs Back-to-Back Fundraising Events

The Public Relations and Fundraising Office at The Arc of Warren County is always extremely busy, and in summertime it is even more bustling with activity. In June, the 31st Annual Radiothon with WRNJ was held. The Arc of Warren County was extremely fortunate to have Norman Worth, of WRNJ, and Jim Travis, of SASCO Otterstedt and a Board member of The Arc of Warren County, serve as co-chairs for the third year in a row. This was the second year that we held our phone bank remotely with great results! Words cannot express how thankful The Arc of Warren County community is that WRNJ has supported this initiative for many years and continues to do so.

“Norman Worth and Jim Travis have been a blessing to our Agency,” says John Whitehead, CEO. “They have

supported us and understand the importance of advancing our mission to serve people with intellectual and developmental disabilities in Warren County.”

The next Radiothon will be held on Wednesday, June 8, 2022 and Norman Worth and Jim Travis will serve as co-chairs once again.

The Triathlon with DASH Multi-sport was held on July 17, 2021 at Mountain Lake in Liberty Township. It was a beautiful day to spread awareness about our organization. One hundred twenty-eight people registered for this event and it was a pleasant experience for all involved. The Agency has plans to hold another Triathlon on July 16, 2022.

The Third Annual Food Truck Fest was held at Donaldson Farms just one week after the Triathlon. This event has become one of our signature events that really draws individuals from the community from near and far. The Agency is very fortunate to be able to work with The Arc Foundation Board member, Katie Donaldson, on this initiative. The next year’s Food Truck

Fest will take place on July 23, 2022.

We would like to send out a special thank you to all of our Food Truck sponsors:

- The House of the Good Shepherd (*Biergarten Sponsorship*)
- John Johnson Auto Group (*Music Sponsor*)
- Mutual of America (*Hayride Sponsor*)
- Hunterdon Healthcare (*Greeting Sponsor*)
- Valley Plumbing, Heating, Cooling & Lawn Sprinklers, LLC. (*Cooling Tent Sponsor*)
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- AssuredPartners Inc./Walsh Benefits (*Friendship Plus*)
- Czig Meister

Much appreciation to the following organizations that are Friendship Sponsors:

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David Santini, CPA, LLC.
TGM Services
Unity Bank
Viking Pest Control
Mark Zgoda, Architect



Triathlon 2021



The Golf Classic Garnered Successful Results

Save The Date for The Arc of Warren County Golf Classic on September 12, 2022!

Weeks after The Third Annual Food Fest, The Arc of Warren County held a Golf Classic with The House of the Good Shepherd for the second year. Each organization raised over \$15,000 as a result of this fundraiser. Next year, The Arc of Warren County will run a Golf Classic on September 12, 2022 at Hawk Pointe Golf Club once again. Eighty-six golfers attended and Norman Worth, of WRNJ, served as emcee.

A special thank you goes to our many sponsors and that includes

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- Blue Ridge Lumber
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- George Salamy, *Board Member of The Arc of Warren County*
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- TQM – Total Quality Medical, Inc.

And our Hole in One Sponsors....

- Rossi Auto Group
- Smith Motor Company

Thank you so much to Glenn Beyerl, from KPM Exceptional, for sponsoring a foursome of The Arc of Warren County consumers and their Direct Support Professionals and our many tee sign sponsors and individuals and businesses who donated gifts.

“This was the first time that we have had our residents golf at one of our Golf Classics,” says Reni Piperata, LPN. “It was such a wonderful experience for them and really made such a positive impact that they had the opportunity to participate in this fundraiser.”

Thank you to The House of the Good Shepherd for partnering with us for the past two years. Next year, we are holding The Arc of Warren County Golf Classic on September 12, 2022 at

Hawk Pointe once again. It will be the first time we have held a Golf Classic on our own since 2018. Please consider joining us.



Robyn Jensen of Edward Jones, a Bronze Sponsor of The Golf Classic (far right) is pictured with Peggy Burke (middle) and Hollie Driscoll, CFO of The House of the Good Shepherd.

Save the Date

Save the Date of **March 3, 2022** for The Arc of Warren County's Award Ceremony at Bello Giorno Restaurant.

If there is someone whom you have in mind that you would like to be considered for an award, please reach out to alalevee@arcwarren.org



Grant Awards for The Arc of Warren County



Marci Gubich, Director of Recreation for The Arc of Warren County (right) is pictured with Elizabeth Spann, an Arc consumer at the Rhythm 'N Sound concert (photo credit: P. Speth)

The Arc of Warren County has been fortunate to have received some grants recently. We would like to thank the following organizations for their grants:

Atlantic Health/Hackettstown Medical Center – for a grant of \$1,709 for equipment for Camp Warren and our Day Programs to promote healthy living.

Greenwich Autism Alliance – for a grant of \$3,000 for equipment for Camp Warren and the cost of Camp tee shirts.

Warren County Cultural and Heritage

Commission – for a matching grant of \$1,500 for art materials, art classes and a concert for our consumers. As a result, our consumers recently had the opportunity to enjoy a concert at Camp Warren to celebrate the end of the summer and the beginning of fall. It was a wonderful opportunity to utilize the space and enjoy the music of Rhythm 'N Sound.

Membership Breakfast

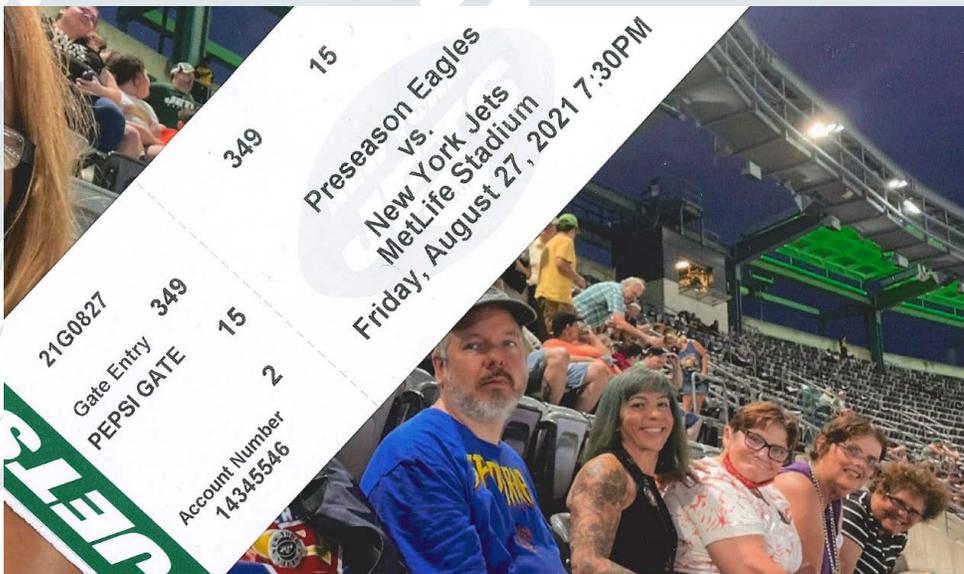
Let's get together for a meet and greet breakfast for our Arc of Warren County members.

The date is November 19, 2021 at 9 a.m. Please RSVP to Erin Stritch at estrich@arcwarren.org if you are interested.

Go Jets!

The Arc of Warren County consumers and their staff from Gardner Court Supervised Apartments, as well as Corliss Group Home, had a wonderful time at the Jets game in late August.

Thank you so much to Mike Donowick, Arc Foundation Board Member and The Special Needs Ministry at St. Luke's Church in Long Valley, for generously providing The Arc with this opportunity.



Annual Appeal

In the near future, you will receive The Arc of Warren County's Annual Appeal in the mail. Please consider supporting The Arc of Warren County as we conclude our 67th year as an Agency. Donations can be submitted online at arcwarren.org or by mail to 319 West Washington Avenue, Washington, NJ 07882.