



THE NEWSLETTER OF PLANNED LIFETIME ASSISTANCE NETWORK OF NEW JERSEY

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Parent Advocate Becomes PLAN|NJ President

Long-standing board member **Peter A. Phillips**, CPA was elected President of the PLAN|NJ Board of Directors during the Annual Meeting in June. Peter and his wife, Judy are the parents of Peter Jr., 47, and Elizabeth (Beth), 42, both of whom have intellectual and developmental disabilities.

Judy and Peter are intimately involved in the lives of both children. Peter Jr. lives in a group home and enjoys social activities which, though curtailed due to the pandemic, still include swimming and walking in the park with his housemates. Beth prefers to live alone and is supported by a team of Direct Support Professionals who are in daily contact with her parents regarding her insulin-dependent

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Historic Year Brings Positive Growth and Change to PLAN|NJ

A Letter from Ellen Nalven, *Executive Director*

In times of crisis, people with significant disabilities are often neglected in the hierarchy of emergency response, but PLAN|NJ's support remains unwavering and essential. Recent public health and social upheavals have increased our work's urgency and complexity. In response, we have implemented solutions to ensure even greater safety, security, equity and access to quality supports for families and loved ones.

The COVID-19 pandemic required us to pivot quickly to protect our clients and staff and continue operations uninterrupted. From a distance, our social services team and residential staff allies assessed each individual's health, safety, daily needs and well-being. They also determined the protocols residential staff were taking to keep residents safe.

We experienced a dramatic increase in the number of families inquiring about quickly completing a LifePLAN to secure all critical communications for their loved ones. Life planning consultations are now conducted virtually and we instituted policies and procedures to convert to a work-from-home model. Support from the E. J. Grassmann Trust, the Hyde and Watson Foundation and the NJ Manufacturers Insurance Company



helped us bring our offices, client services and communication tools online.

With monthly in-person visits prohibited, we made weekly wellness calls to clients we serve as Guardian, and others who rely on home visit monitoring. We established safety modifications and protocols for those with COVID-19 symptoms, positive tests or exposure to it. Along with the disability rights community, we successfully advocated for hospital protocols for off- and on-site support and patient care as medically necessary. While several individuals we support did become ill, thankfully we have not lost anyone to COVID-19.

Our statewide educational seminars quickly shifted to a virtual

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PLAN|NJ Elects New Officers

The Board of Directors elected new officers at the June 2020 Annual Meeting. They are:

Peter A. Phillips, CPA, *President*

Theodore R. Goyins, Jr.,
Vice-President

Thomas J. Zesk, *Treasurer*

Ellie Byra, *Secretary*

Samantha J. Herrick, Ph.D.,
Immediate Past President

Board Members:

Linda Buch

Goldie Ellis

Elizabeth G. Farishian

L. Randolph Hood, CFA

Beth C. Manes, Esq.

Michael P. McGarry

Adam Wilson, Esq.

Joseph B. Young, Esq.

For more information on each individual's qualifications and accomplishments, visit <https://www.plannj.org/board-of-directors/>

Historic Year (continued from page 1)

platform. Staff mastered a web-based meeting application and we delivered our first webinar within weeks. This format now allows us to reach many more families to address their life planning, estate, trust, Guardianship and legal decision-making needs. We are grateful for the emergency grant from the NJ State Bar Foundation which supported this work and to True Link Financial for training and technical assistance.

The PLAN|NJ Board committed to address systemic racism through direct action and program expansions following the killing of George Floyd and others. We have enhanced our grant funded pro bono services for Black and Brown people with disabilities and their families. Families are referred to our in-house committee and to a pilot program in partnership with the Family Support Organization of Essex County (FSOEC). We are expanding our life planning consultation services to a small number of families. Please refer those who may benefit to us at

908-575-8300 ext. 28.

In late August, we returned to office-based work. It is helpful to see people "live," even with masks on and continued vigilance about social distancing and other health protocols.

Happily, our Social Services staff resumed monthly in-person visits with Guardianship and Home Visit Monitoring clients. These visits (and continued weekly wellness calls) cheer our clients and increase their sense of connection, motivation, self-determination and independence. We continue to manage our trust portfolio with the long-term life of each person in mind. We help families create an answer to the question, "Who will care for my loved one when I am gone?"

As we consider the extraordinary events of 2020, I am grateful for the many reminders of our shared humanity and purpose, the can-do attitudes of our staff and Board, and innovative solutions to serve more individuals and families, despite the challenges. Our doors and hearts will always remain open, today and in the future.

Parent Advocate (continued from page 1)

diabetes and related complications. Pre-pandemic, she enjoyed her flower-arranging classes and two weeks at summer camp. "There is a lot of anxiety now because we don't know what's coming when the weather turns colder and they can't participate in the activities they enjoy. We are doing all we can to ensure each of our children has a thriving life in a safe environment," Peter said.

Born in New Jersey, Peter grew up in Bayonne and attended college in Jersey City before qualifying as a certified public accountant. His career spanned more than thirty years with major firms and his own successful medical supply business. Today he offers consulting services exclusively to non-profit organizations and donates his time to helping



adults with disabilities. More of his background can be found at <https://www.plannj.org/board-of-directors/>.

Regina Tegeler, former member of the PLAN|NJ Board of Directors, said, "Peter and I have visited several New Jersey local and federal legislators' offices, and his input on budgets and financial impacts for our loved ones is expert. These legislators value his input and have worked to help

us create good lives for people with developmental disabilities in New Jersey, and in the United States."

"I find it very rewarding to see how things have changed over the years. I am extremely honored and excited to have been chosen as president of PLAN|NJ. It may be the best run of all of the nonprofits I've seen," Peter said. "Many of the challenges of the pandemic and social unrest may seem daunting, but I am confident our management team will continue to provide quality services to our clients. Our Trust portfolios are doing well, which means our kids (PLAN|NJ clients) are doing well, and we have the opportunity to help more people with disabilities. We are risk-averse, conservative investors because we are in it for the long haul. Our clients need this money to last a lifetime," he said.

FAMILY VOICES

Determination Alongside an Arabian Horse

By Olivia Rae Vargas

My name is Olivia Rae Vargas. I am 12 years old. At birth, I was diagnosed with Treacher Collins Syndrome, a rare genetic disorder which affects the development of my facial bones. Doctors informed my parents my life expectancy is approximately the same as anyone else, though every case is different. I am mostly known for my hearing impairment or my fashionable hearing aids, but what you don't know is at 16-months old,



I was unresponsive and rushed to the hospital, where I was trached and put on life support for almost two months. Luckily, I pulled through, but my battle wasn't over yet. Throughout the next year and a half, I received countless surgeries, hospitalizations, treatments, and therapies to try to stabilize my airway so I could breathe and function normally.

At three years old, one-third of my life had been spent inside of hospital walls. To date, I have received more than 20 surgeries and will continue throughout my adolescence.

I have grown much stronger and found a new love – horses. As you know, every princess needs her horse. In October of 2016, I learned to take care of horses as equine therapy. Shortly after, with great encouragement, I began to ride. Up until 2018, I wasn't able to compete as much as I wanted to due to ongoing surgeries, but luckily I was able to qualify and attend youth nationals. I trained really hard and was able to accomplish my dream: I became the 2019 US National Champion in Arabian & Half Arabian Hunt Seat Equitation Not to Jump Walk Trot 10 and Under at Arabian Horse Association Youth Nationals, held in Oklahoma City, OK.



Adapted from an article previously published in ArabianCentric and used with the permission of Olivia Rae Vargas and family.



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Thanks for your generous support!

PLANINJ's
Celebration
of Abilities
Moves to 2021

 2021 CELEBRATION
of ABILITIES

SAVE THE DATE: THURSDAY, MAY 20, 2021

Please join us – in person or virtually via a live stream — to recognize NJ disability rights champions and raise support for life-long care for more individuals with disabilities.

Our host venue will follow all health/safety protocols to protect public health.

Stay tuned for more details!



plan|NJ

Lifetime Advocacy for People
with Disabilities

P.O. Box 547
Somerville, NJ 08876-0547
Phone: (908) 575-8300
Fax: (908) 927-9010
Email: info@plannj.org
Web: www.plannj.org

YES! I want to help PLAN|NJ support individuals and their families with the legal and financial planning, care coordination, and self-determination guidance they need and deserve. Enclosed is my tax-deductible donation of:

\$150 \$100 \$50 \$35 Other _____

In Honor of or In Memory of (please check one and print name): _____

In addition

I would like to learn more about establishing a bequest

I have included PLAN|NJ in my estate plans

I would like to include PLAN|NJ in my estate plans

I would like to establish a tax-free IRA rollover

Name _____

Address _____

City _____ State _____ Zip _____

Please make your donation today! Visit plannj.org, click on 'Donate,' and add your payment method and contact information to complete. Or, you may make your check payable to PLAN|NJ and mail it to PLAN|NJ, P.O. Box 547, Somerville, NJ 08876-0547. We reserve the right to publish donor names in the PLAN|NJ Annual Report unless otherwise requested.

If you would like your name removed from the donor list, please check here: _____

For more information please contact Kerry Lee at 908-575-8300 ext.21 or kerry.lee@plannj.org