



STEP AHEAD NEWSLETTER

Fall 2021

From the Executive Director

Hello TNSTEP Community:

Autumn is in the air, and that means sweaters and sweatshirts, cool evening walks, shorter days, leaves turning gorgeous colors, and pumpkin spice items everywhere! But it also means that the 2021-22 school year is well under way, with all of its opportunities and anxieties. The pandemic is still a major factor, school COVID-19 policies are all over the place, and apt to change quickly. We “feel the pain” of families who are struggling with ensuring their students with disabilities continue to make progress, as well as enjoy their days.

Please know that TNSTEP staff are always here to help you work through any special education issues you or your child may be having during this extended, challenging time. You will find our contact information on the last page of this Newsletter.

In this Fall issue we’re covering a lot of bases, as we continue to provide information that has been requested or that we think will be beneficial to our community. You’ll find articles about our exciting STEP Up to the Plate Youth Council; the development of a Family Advocacy Forum, a collaboration between our agency and the Tennessee Disability Coalition; and a new grant from the Tennessee Department of Human Services that will train School Resource Officers on the impact of ACEs (Adverse Childhood Experiences) and Tennessee’s Building Strong Brains initiative. We also feature a timely and important piece on post-COVID syndrome, which too often affects our children and youth.

We hope you like what you see here, and that the TNSTEP quarterly Newsletter, in general, is a valuable resource. We appreciate hearing your thoughts – positive and negative – so we know we’re on track or what we can do better to serve you.

Gratefully,

Karen Harrison

Executive Director, TNSTEP



Family Advocacy Forums: Coming in 2022!

TNSTEP and the Tennessee Disability Coalition (TDC) are partnering on a new initiative designed to increase families’ ability to advocate for equitable resources, supports, training, policies, and processes for their children and youth with disabilities. It’s essential that families have a voice in policies and practices that are related to the education, health, safety, and well-being of children and youth with disabilities. The Family Advocacy Forums (FAF) will provide a platform for interactive discussions on important issues, easy to use tools, and training to prepare participants to actively engage in school and community reform.

Forums will address topics based on hot button issues that arise throughout the year. By combining TDC’s expertise in impacting policy, TNSTEP’s expertise in federal and state special education laws and practices, and families’ expertise and lived experiences in what is important for their children with disabilities to thrive at home, in school, and in the community, we hope to have a positive impact in areas such as school discipline, mental health services, equity, inclusion, education, and much more.

Having information is GREAT! Putting that information into action is VITAL, to get to the outcomes we all want for individuals with disabilities. If you’re interested in being part of the FAF Design Group to help shape this new initiative, please email karen.harrison@tnstep.org. We look forward to sharing more information on how to join this action-oriented series in coming months. To ensure you are in the know, join our FAF listserv at tnstep.org/involved/#family-advocacy-forums.



GETTING TO KNOW POST-COVID SYNDROME
By Demetrio Macariola MD, Professor in Pediatrics
Director, Division of Infectious Diseases, ETSU Quillen Medical College

The SARS COVID 19 virus has totally changed our way of life. Nowadays, we have to think about COVID when we go outside our houses, travel, and interact with people around us. This virus seems to keep us from expressing our usual gestures of affection; we have to think twice when shaking hands or hugging people around us.

According to the World Health Organization, worldwide, there are more than 232 million reported infections with four million deaths. In the U.S., based on data from the Center for Disease Control, there are more than four million cases, with deaths close to 680,000. Indeed, we must take this virus very seriously.

If we get infected, it can sometimes affect us in horrific ways. COVID symptoms usually appear 2-14 days after exposure to the virus. It may cause fever or chills, cough, difficulty breathing, fatigue, body aches, headache, loss of taste or smell, sore throat, runny nose, nausea, vomiting, or diarrhea. The initial symptoms seem benign, just like any ordinary viral infections. For mild illness, the duration of COVID infections lasts for 10-14 days. For severe illness, it can last for several weeks, depending on the organ systems involved.

If someone survives from a COVID infection, there may be lingering health issues. When the symptoms following infection go beyond four weeks, and cannot be attributed to any other illness, it is called “post-COVID syndrome.” Post-COVID syndrome may affect both children and adults. It can affect different organ systems such as the lungs, blood, heart, brain, kidneys, endocrine glands, and skin. Reported duration of post-COVID syndrome may last up to 12 weeks. Predominant symptoms are fatigue (53%), shortness of breath (43%), joint pain (27%), and chest pain (22 %). Fatigue, shortness of breath, and chest pains are common symptoms, since both the heart and lungs are affected. There are other manifestations affecting the different organ systems involved, as demonstrated in the table below:

ORGAN SYSTEM	MANIFESTATION
Lungs	Shortness of breath, decreased exercise tolerance
Blood	Increased blood clots
Heart	Palpitations, chest pains, shortness of breath
Brain	Headaches, cognitive impairment, muscle aches
Kidneys	Impaired kidney function
Endocrine gland	Diabetes mellitus, thyroid and bone disorders
Skin	Hair loss

There is scarring that may occur in the lungs after COVID infection which causes shortness of breath during physical activity. Blood clots can easily develop, which is why patients may need blood thinners. The heart muscles can be damaged causing abnormal heart rhythm. There is cognitive brain impairment called “brain fog”. For those patients with COVID that ended up needing intensive care, five percent ended up having kidney injury. Twenty percent of COVID patients experience hair loss.

There is a complication of COVID infection called multisystem inflammatory syndrome in children (MISC). This may happen even two months after getting the infection. MISC presents with fever, eye redness, rashes,

joint pains, redness of the mouth and throat, enlarged neck lymph glands, and swelling of the hands and feet. This COVID complication also has the potential of damaging the heart.

Indeed, COVID infection should not be taken lightly. Its effect on an infected individual may occur even for several weeks after the initial illness. It’s very important for anyone who has had a COVID infection to have close follow-ups with their physician, so that if post COVID syndrome develops, it will be recognized and an adequate intervention can be initiated. The intervention provided will depend on the organ system involved. Finally, getting vaccinated against COVID is a smart step that each one of us should take to prevent COVID infection and post-COVID syndrome.

TNSTEP Tip: If you have a school-age child that you suspect may be experiencing post-covid symptoms and need additional supports in school. contact your school principal and ask to discuss accommodations under a 504 plan or supports through an Individualized Education Program (IEP).

MEET TNSTEP's STEP UP TO THE PLATE YOUTH COUNCIL MEMBERS

We are so pleased to report that our STEP Up to the Plate (SUTP) Youth Council is underway, and exciting things are happening already! Our two Youth Council Members, Lily Bennett and Eric L. Massey, who you'll meet below, are enthusiastic, engaged, and ready to lead TNSTEP's youth outreach activities.

We have an awesome team on the TNSTEP side, which includes Lisa Gosnell, Joey Ellis, Stephanie Willis, and Ned Andrew Solomon. Each SUTP Adult Advisor has a unique set of skills to contribute to this initiative. Our hope is that the Youth Council Members will learn from us, as we learn from them.

In their short time, Lily and Eric have completed assignments, including developing their own bios and filming a YouTube video to promote SUTP. Soon they'll be writing articles for this Newsletter and participating in a FB Live Coffee Chat. We all meet once a month, which provides an opportunity for the Youth Council Members to talk about their passions, concerns, and issues that are important to them, and likely important to other youth who experience disabilities. Lily and Eric are enjoying their SUTP earnings, too. They are paid a stipend for attending meetings, completing assignments, and participating in SUTP activities. It's a win-win for all of us! Here they are in their own, empowered voices:

Hi, my name is Lily Bennett. I was born in Florida, but I grew up overseas in Canada and Saudi Arabia. This summer I saw an email about the opportunity about STEP Up and thought it would be a great experience.

I joined the Youth Council because I want to help others that are not as fortunate as me. I want to learn both leadership skills and how to help others. I love to do photography, and watch the sunset. Before I joined STEP Up I worked at River Rat, in Townsend, Tennessee. This job most definitely made me learn how to get a job done, on time, and keep up with my responsibilities. The majority of my time there was spent making sure people got life jackets and were safe on the river.

I was a part of Junior Reserve Officer Training Corps, which taught me about how to lead, and step up when I'm needed. I delivered speeches about my stroke and how it effected me to University of Tennessee nursing students for three semesters. I was also a peer mentor for special education students in middle school.

It's hard to talk about why you're awesome in your own eyes, so when I asked my mom what she thought she said, "you are an overcomer, and a very determined person, while also being very happy-go-lucky at the same time."



I am Eric L. Massey, a 17-year-old senior from Memphis. I have been homeschooled since the second grade through Homelife Academy, and I am looking forward to attending college next year.

One of my main interests is fitness and I enjoy helping others stay healthy. My favorite sport is swimming! I compete for three different swimming programs including the Memphis-area Home Education Association high school team, Memphis Tigers YMCA Swim Club, and Special Olympics. In June 2020, I received a USA Today All-Star Preps Award for Special Olympics Athlete of the Year in Memphis. Recently I was selected as a member of Team Tennessee to compete as a swimmer at the Special Olympics USA Games

in Orlando, FL in June 2022!

I am the first Special Olympics International Health Messenger from the state of Tennessee. As a Health Messenger, I teach inclusive health information to fellow athletes, corporate partners, and community members. I also started my own fitness club called iRev, which is short for Inclusion Revolution.

I first learned about SUTP from my mom's friend who thought it was another great opportunity for me to work on leadership skills and inclusion activities. I hope to share ideas about health and fitness with youth with and without disabilities. I also want to learn ways to be a better leader.

To find out more about STEP Up to the Plate, including participating as a SUTP Youth Council Member, please contact Ned Andrew Solomon at nedandrew.solomon@tnstep.org.

Creating Supportive School and Community Environments

A new TNSTEP grant, funded by the Tennessee Department of Children Services (DCS), will address the unique need that exists for families, school resource officers (SROs), school safety teams, school administrators, and the community to understand the impact officers in schools have on the lives of children and youth with disabilities.

Through training and skill building, participants will gain an understanding of how SROs function in schools, and the need to promote positive interactions. Families will be provided information on the role of SROs and how to share information about their children to lead to students being provided effective supports on the school campus. Finally, the community will be engaged in positive messaging and outreach to be supportive of the schools and families in their communities, with a focus on families of children with disabilities and youth who have been dually impacted by disability and adverse childhood experiences (ACEs).

The purpose of the project is to address the principles set forth by DCS through its Building Strong Brains Tennessee/ACEs initiatives. TN STEP understands that ACEs can negatively impact the architecture of the developing brain, which is shaped by the interaction between genes and experiences. We will be a partner in this important work to help communities provide safe, stable, and nurturing environments where children can develop the social, emotional, and behavioral skills they need to secure long-term health, succeed in school and life, and contribute to the shared future of Tennessee. In our work with families and students through our Parent Training and Information Center, we know that families, caregivers, and communities play a key role in preventing, mitigating, or helping individuals recover from ACEs, which is essential as Tennessee moves toward a future that promotes increased health and wellness for its citizens.

The project will address the following areas:

Programs and services related to five protective factors: parent resilience; social connections; concrete support in time of need; providing resources to the school and community to support children and families through increased awareness of the impact of disability and ACEs; and skill-building for families, students, educators, and community service providers.

Professional practices to engage educators and those individuals within schools, such as SROs, who have a direct impact on the development of young children during sensitive times of brain development, and teenagers who are shaping their behaviors related to interactions with authority figures that will follow them into their adult lives.

Conditions that exist in the school and community related to how students with disabilities who exhibit challenging behaviors are treated when there is not a clear understanding of their needs, and how to effectively support them to become healthy, happy, and productive adults.

The project will focus on an area of need where a gap has been identified, specifically for schools to address the training needs of families, SROs, school safety teams, administrators, and the community, related to understanding the impact SROs have on the lives of children and youth with disabilities in schools, while working toward developing positive interactions that will promote the overall health and well-being of children and families.

The project will also engage participants from community organizations, businesses, non-profit organizations, faith-based organizations, and other entities, both urban and rural, in community awareness and resource sharing related to the role of SROs in schools and how disability and ACEs impact families in their communities.

Throughout this project, TNSTEP will share updates through this Newsletter and social media.

If you would like to learn more, be involved in this initiative, or request training, please contact Shuntea Price, Project Director, at shuntea.price@tnstep.org.



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