

Gulf Coast Epilepsy Alliance (GCEA)

3rd Annual Butterfly Release, 2023



You're invited! Come join **Gulf Coast Epilepsy Alliance (GCEA)** for a **FUN** afternoon in the park (indoors & outdoors) to recognize super-hero lifesavers for October SUDEP-Epilepsy Awareness Month.

Enjoy a **LIVE** butterfly release, music, a pop-up market, puppy therapy, a silent auction, food trucks, a photo booth, face-painting and friendship, all while supporting GCEA's programs, raising SUDEP awareness and learning how to keep those with epilepsy seizure-**SAFE**.

Event Speakers/Physician Advisors:

Todd Masel, MD, UT Medical Branch at Galveston, Texas Hina Dave, MD, UT Health at Houston, Texas

Sunday, October 8, 2023 ♦ 2 pm - 5 pm
Wayne Johnson Community Center

Carbide Park @ 4102 Main Street, La Marque, Texas 77568

*Register for **FREE** Event Tickets ~ consider an Event Sponsorship!

GCEATX.org/events ~ 409.299.5559







Who is GCEA?

Est. 2019, founded by Shena and <u>Trysten Pearson</u>, Gulf Coast Epilepsy Alliance (GCEA) is a local nonprofit that provides direct services to individuals with seizure disorders and those touched by epilepsy in the **Texas Gulf Coast**.

After <u>Trysten's</u> diagnosis of epilepsy at age 12, a five-year partnership with the Epilepsy Foundation Texas – Houston/Dallas-Fort Worth/West Texas, advocating for the passage of <u>Sam's Law for Texas Schools</u>, raising <u>SUDEP awareness in the New York Times</u>, and receiving rank of **Eagle** with the <u>Boy Scouts of America</u>, Trysten established GCEA to support and improve the quality of life for people with epilepsy in Texas.

Our vision is to achieve a society where no person's life is limited by epilepsy.

GCEA is a 501(c)(3) nonprofit organization, all contributions are tax deductible. [EIN# 84-2099498] To learn more, visit: **gceaTX.org**

What is SUDEP? What is Epilepsy?

For many people living with epilepsy, the risk of Sudden Unexpected Death in Epilepsy (SUDEP) is a very important concern. SUDEP refers to deaths in people with epilepsy that are not caused by injury, drowning, or other known causes. Every October, we raise awareness of SUDEP and learn how to keep those with seizure disorders or epilepsy **seizure-SAFE**.

Epilepsy, also known as a seizure disorder, is a common neurological condition characterized by recurrent seizures.

- ~ 1-in-10 may have a seizure during his or her lifetime.
- ~ 1-in-26 people in the United States will develop epilepsy
- ~ 3 Million US adults & 470,000 children have epilepsy
- ~ Number of Cases in TEXAS (all ages) = over 293,000

(source: cdc.gov/epilepsy)





*Register for <u>FREE</u> tickets or become an Event Sponsor!

For updates, visit **gceatx.org/events**For questions, call **409.299.5559**

How do I participate?

- 1. Register for **FREE** event tickets (required per person) on our GCEA website, events page.
- 2. Optional: Release a **LIVE** Butterfly-in-a-Box (\$25 donation) **or** pay-it-forward and give a GCEA Youth Ambassador the opportunity to release a butterfly on your behalf (\$50 donation).
- 3. Purchase a Butterfly T-Shirt in our online **Gift Shop** or wear purple on Oct. 8.
- Please consider becoming an Event Sponsor (pick a level, donate online, and email your LOGO to <u>info@gceaTX.org</u> by <u>September 15th</u>)

We would love to see you, your friends, family, and caregivers come join us! Registration is required and everyone is welcome to our ALL-INCLUSIVE event!

For event details sent to your cell phone, text the word **BUTTERFLY** to

409.207.7768





SPONSORSHIP LEVELS

FOR HOSPITALS, PHARMA COS. & LARGE BUSINESS

A Purple Emperor Butterfly \$7,500 = 10 Live Butterflies to Release

Reserved seating, your marketing materials on a resource table/vendor booth, name recognition during the event, your logo in our newsletter & all listed below... [8 offers]

Your company featured on <u>social media</u> & in <u>ads;</u> logo printed on <u>event T-Shirts</u> & all listed below...

A Blue Morpho Butterfly
 \$5,000 = 8 Live Butterflies to Release

Your company <u>logo on printed materials</u> & featured on our <u>GCEA event banner</u> & all listed below... [4 offers]

Reserved seating, your company logo <u>promoted on our</u> <u>website</u> at <u>gceaTX.org</u>



SPONSORSHIP LEVELS

FOR GCEA FRIENDS, MEMBERS

& SMALL BUSINESS

❖ A Grand Birdwing Butterfly

\$1,000 = 10 Live Butterflies to Release

Reserved seating, your company featured on social media & in ads; logo printed on event T-Shirts & all listed below... [6 offers]

A Vivid Monarch Butterfly \$500 = 3 Live Butterflies to Release

Indoor open seating, your company <u>logo on</u> <u>printed materials</u> & featured on our <u>GCEA event</u> <u>banner</u> & all listed below... [4 offers]

A Little Metalmark Butterfly \$250 = 4 Live Butterflies to Release

Indoor open seating, your company logo <u>promoted on</u> <u>our website</u> at <u>www.gceaTX.org</u>





Gulf Coast Epilepsy Alliance (GCEA)

Butterfly Release, 2023



EVENT PROGRAM

Welcome & Opening:

Betsy Furler, GCEA Executive Committee Danielle Lance, GCEA Board President Abigail Beer, GCEA Board Vice President



SUDEP & Epilepsy: Todd Masel, MD, UTMB Neurology

G.E.M. Honorees: Shena Daly Pearson, GCEA Executive Director

Closing and Prayer: Doreen Hughes & Pastor Jervie Windom

LIVE Butterfly Release: Trysten Pearson, GCEA Founder

Group Photo: Everyone



What can I do to reduce the risk of SUDEP?

The full understanding of Sudden Unexpected Death in Epilepsy (SUDEP) is still unfolding, but there are measures that people with epilepsy and their families can take to minimize risk:

- 1. People with epilepsy should make sure to take the medications prescribed for them to maximize seizure control.
- 2. If medicines are not effective, consider other therapies such as surgical options, dietary options, research drug trials, or devices/technologies that may help to enable early intervention when seizure activity occurs.
- 3. Consider supervision or monitoring during sleep hours to identify seizure activity.
- 4. Lead a healthy lifestyle and keep stress to a minimum whenever possible.
- 5. Patients should regularly visit with their doctor, especially if convulsive seizures are not completely controlled.
- 6. Ensure that family members and caregivers have knowledge of seizure first aid and of emergency resuscitation measures including CPR and defibrillator use.

Don't forget to visit our butterfly release photo gallery at gceaTX.org/gallery!



GCEATX.ORG

Why Butterflies?

Celtic mythology regards butterflies as a symbol of the soul.

There's an old Irish saying that butterflies are thought to be able to cross into other realms and represent transformation, creation, and rebirth.



3rd Annual Butterfly Release, Honoring The Memory Of...

2021 ~ Bashan Swain (24 years old)

2022 ~ Henry Furler (22 years old)

2023 ~ Micayla Branin (21 years old) {Sept. 10, 2001 - Dec. 3, 2022}







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OUT AND ABOUT | DOREEN HUGHES

Butterfly release gives wings to information on epilepsy

ct. 24 marked the culmination of the nonprofit Gulf Coast Epilepsy Alliance committee members'



DOREEN HUGHES

work, focus and commitment to shine light on Sudden Unexpected Death in Epilepsy Aware-

and volunteers' hard

ness Month. The group members saw firsthand the fruition of their labor come to life in their first annual Butterfly Release ceremony held at Carbide Park in La Marque.

The powerful and heartwarming ceremony was attended by family, friends and other supporters who shared the common bond of epilepsy. On this sunny afternoon in the park, with the wind blowing and birds chirping, folks gathered under the pavilion to celebrate life with the release of butterflies.

The day highlights the alliance's quest to bring awareness to this often-misunderstood neurological disorder. According to SK Life Science Inc., epilepsy is the fourth most common neurological disorder and affects people of all ages, races and gender. Nearly 50 million people worldwide suffer from epilepsy, including more than 3.4 million people in the United States.

Gulf Coast Epilepsy Alliance President Mike Dudas welcomed guests. In opening remarks, board member Danielle Lance shared the symbolism and meaning of the butterfly release: freedom, growth, change, hope, renewal and the courage to embrace transformations.

"The butterfly has one of the most fascinating life cycles of all creatures," she said. "Before growing into an adult, it goes through



PHOTOS BY GULF COAST EPILEPSY ALLIANCE ADVISORY COMMITTEE MEMBER ELIZABETH SCHOOLER/Courtesy

Gulf Coast Epilepsy Alliance advisory board member Camryn Pitts, left, and founder Trysten Pearson, right, enjoy the butterfly release with Dylan Lutz from under the pavilion at Carbide Park.



The Gulf Coast Epilepsy Alliance board of directors, advisory committee and volunteers gather for a group picture at the recent Butterfly Release ceremony held at Carbide Park in La Marque on Oct. 24.

various stages, constant growth and change."

Todd Masel, a doctor at the University of Texas Medical Branch neurology department, spoke about Sudden Unexpected Death in Epilepsy. Monika Ummat, a doctor with the Houston Neurology Clinic, informed attendees about seizure safety. Also in attendance were Jim Sweeney of Minuteman Press, Bay Area, who made a check presentation to the alliance. Jervie Windom, pastor at Resonate Church in La Marque, conducted prayer and asked all present to practice acceptance and kindness.

The release of the butter-

flies was performed by Trysten Pearson, founder of the Gulf Coast Epilepsy Alliance, who in 2019 led the charge to enact Sam's Law — named after Kilgore Independent School District student Samantha Watkins, who died in December 2016 after having a seizure while on campus. Also assisting with the



Gulf Coast Epilepsy Alliance Vice President Charlene Lozano, front, is joined by Executive Director Shena Pearson, left, and board member Danielle Lance at the alliance's Butterfly Release ceremony held at Carbide Park in La Marque.



Monika Ummat, left, a doctor with the Houston Neurology Clinic, spoke to attendees about seizure safety. She's pictured here with Susan Lautenbach of SK Life Science Inc.

release was his mother, **Shena Pearson**, executive director at the alliance.

Sam's Law was signed by Gov. Greg Abbott on June 11, 2019. The law mandates school district employees who have regular contact with students be trained to recognize seizures and how to administer first aid in a seizure emergency.

Attendees enjoyed

music, delicious food and ice cream served up from various truck vendors who generously donated a portion of their sales back to the alliance. For more information, visit gceatx. org.

Doreen Hughes covers events and happenings across the county. Her column appears in the weekend edition. Contact her at newsroom@galvnews.com with "Out and About" in the subject line

OUT AND AROUT | DOKEEN HOGHES

Epilepsy Alliance celebrates with butterfly release

ulf Coast Epi-lepsy Alliance recently held its second annual Butterfly Release event at Carbide



DORFEN

Park in La Marque. Attendoubled compared with previous years as family

HUGHES

friends, sponsors and community members came to celebrate.

Leigh Ann Moya, a Leigh Ann Moya, a fusion artist, kicked off the celebrations with her interpretation of the butterfly dance that left the audience spellbound. the audience spellbound. Danielle Lance, president of the alliance, welcomed guests and honored the memory of Henry Furl-er. Dr. Zacharia Shebani with the University of Texas Medical Branch Department of Neurol-ogy gave an informative englessy presentation.

epilepsy presentation. Shena Pearson, alliance executive director, performed the award ceremony and recog-nized board and committee members. Lisa Caballero of UT Health Houston and Tammy McCrumb, UTMB Health Galveston, were recognized with The recognized with The Going the Extra Mile awards. Doreen Hughes, Galveston County Daily News columnist, gave thanks and gratitude. Pastor Jervie Windom, with Resonate Church in La Marque, conducted closing prayers.

The ceremonial release of butterflies represented hope, growth, change, renewal, freedom and the courage to embrace the metamorphosis trans-formation of life from caterpillar to butterfly. Gulf Coast Epilepsy Al-liance was co-founded in 2019 by Trysten Pearson

after he experienced his first epileptic seizure in August 2013 at the age of 12. As an advocate for epllepsy awareness, Pearson has delivered more than 50 presentations since his diagnosis through his Boy Scout Troop 192. The alliance's mission is to work for and meet the needs of people with epilepsy, their families and their caregivers on the Texas Gulf Coast. Out and About will

Doreen Hughes covers events and happenings across the county. Her column appears each Sunday. Contact her at newsroom@galvnews.com with "Out and About"

return Jan. 21.



DOREEN HUGHES/For The D From left are Jim Marvin, parents Betsy and Eric Furler and Montie Marvin, family and friends of the late Henry Furler, who was honored in memory at the second annual Butterfly Release event held at Carbide Park in La Marque.



DOREEN HUGHES/For The Daily News From left: Allison Rollins, U.B senior neurology provider liaison; Dr. Zacharia Shebani with the University of Texas Medical Branch Health Department of Neurology, Ryan Veselka, Sk. Life Science; and Cindy Tilley, Neurology Integrated Care manager for Fisal less than the Polymer of Polymer Shebang and Polymer of Polymer Shebang and Polymer of Polymer Inc., show their support at the second annual Butterfly Release event in La Marque.



MIKEY LOE/Courtes Gulf Coast Epilepsy Alliance committee members gather for a group picture at their second annual Butterfly Release event held at Carbide Park in La



ELIZABETH SCHOOLER/Courtesy Dr. Patrick Karas, with the UTMB Health Department of Neurosurgery, shares the release of his butterfly with his wife, Tiffany Hoang, and daughter Isla Karas at Gulf Coast Epilepsy Alliance's second annual Butterfly Release event.



MIKEY LOE/Courtes Stevie Lozano gets her face painted by local artist Deb Miller Deats at Gulf Coast Epilepsy Alliance second annual Butterfly Release event.







