

Prepared By: Dana’s Angels Research Trust (DART)

 [www.DanasAngels.org](http://www.DanasAngels.org)

Contact: Jenifer Howard | 203-273-4246 For Immediate Release

 jhoward@jhowardpr.com

**6th Annual DART to the Finish Charity Walk Scheduled for Saturday, September 30, at Greenwich Point Park**

*Family-Friendly Charity Walk Raises Funds for Rare Childhood Disease, Niemann-Pick Type C, Also Known as Childhood Alzheimer’s*

**GREENWICH**, Conn., August 10, 2023 – **Dana’s Angels Research Trust (DART)**, the nonprofit dedicated to funding medical research, education and treatment of the rare childhood disease Niemann-Pick Type C disease (NPC), often referred to as “childhood Alzheimer’s,” and other similar genetic diseases, is hosting its sixth annual **DART to the Finish Charity Walk,** on **Saturday, September 30, 2023**, **at 9:00 a.m**., at Greenwich Point Park in Old Greenwich, Connecticut. This family-friendly and accessible two-mile walk is $30 for adults 22 years and older, $15 for 10-to-21 years old, and children 10 years old or younger are free. Virtual walkers from anywhere in the world are also welcome to join and can register with a $30 donation to DART. **To learn more and register, visit** [danasangels.org](http://danasangels.org) **or** [dartevents.org](http://walk.danasangels.org).

“We are so excited to be hosting our sixth annual DART to the Finish Charity Walk on Saturday, September 30th,” said Andrea Marella, co-founder of DART. “The Walk brings together friends, family, sponsors, donors and the whole community for a beautiful morning at Greenwich Point Park where the money raised goes directly to support crucial Niemann-Pick Type C disease research. We thank everyone who has supported us these past 21 years since we founded DART in 2002 after the NPC diagnosis of our daughter Dana and subsequently our youngest son Andrew.”

Dana Marella was the original inspiration for DART after she was diagnosed with NPC at the age of eight. Once an energetic, happy little girl, Dana eventually lost all her abilities and was confined to a wheelchair. She was unable to walk, talk, had a feeding tube and received a tracheostomy. Despite her severe challenges and numerous hospitalizations, she never lost her sweet nature, always reaching to hold a hand, making her so deeply loved by all who knew her. Her strength and perseverance were a constant inspiration and taught everyone around her the true meaning of life and to appreciate each day. She fought a courageous battle for the 12 years after she was diagnosed. Sadly, she passed away in 2013, just 11 days shy of celebrating her 20th birthday.

In 2004, just two years after Dana was diagnosed, the Marella’s youngest child Andrew was also diagnosed with NPC at the age of five. Andrew recently celebrated his 24th birthday in June and is faring much better, due to taking part in clinical trials that DART has helped fund and spearhead in the past 21 years. Today Andrew proudly works at the Prospector Theater in Ridgefield, Connecticut, as an usher, among other positions at the venue, which is known for providing competitive and inclusive employment for adults and teens with disabilities.

“Andrew has been taking part in a clinical trial administered by the NIH and is on two different medications — cyclodextrin and miglustat - which have helped hold at bay certain aspects of the disease,” noted Phil Marella, co-founder of DART and Andrew’s dad. “DART has been solely focused on finding better treatments and ultimately a cure for NPC. When Dana was diagnosed, little was known about NPC and there were no treatments, no clinical trials and no hope. Most children with NPC passed away in their early teens. Today, with the help of DART and our partners, we have changed that fate.”

DART has helped spearhead eight clinical drug trials and develop the first-ever newborn blood test for early diagnosis of NPC. The NPC community is currently working with the FDA on approving four treatments, two of which have benefitted the Marella’s son Andrew and many other children with NPC. NPC is so rare that only about 200 children in the U.S. have been diagnosed with the disease, and only a few, including Andrew, live in Connecticut. This devastating genetic disorder robs a child of the ability to live a long, healthy life and is often referred to as “childhood Alzheimer’s,” with it often becoming fatal in the teenage years. But DART is helping to change that. As a nonprofit organization, DART’s events like the DART to the Finish Charity Walk, help raise funds to support pivotal NPC research — research that may also help millions suffering from Parkinson’s disease, HIV/Aids, Ebola, heart disease, stroke, Alzheimer’s disease and other disorders that appear to be related to cholesterol. In fact, the two recent FDA approved medications for Alzheimer’s disease were created by pinpointing a genetic biomarker - one of the same that is shared by NPC patients. The next step for NPC research is looking at more than 20 different biomarkers that can help dictate a better path for treatment.

In addition to the clinical trials DART has helped fund, the organization has been instrumental in being part of an NPC Therapy Accelerator program, supporting the work of more than 12 companies currently developing treatments for the disease, three of which are in the later stages of regulatory review with the FDA. The largest newborn pilot testing program in the United States was launched due to the DART and the NPC community — thanks to the leadership of Firefly Fund, a DART partner, its founders the Andrews family of Austin, Texas, and with financial assistance from the Ara Parseghian Fund. The ScreenPlus testing is being led by pediatric genetic expert Dr. Melissa Wasserstein at The Children’s Hospital at Montefiore, in conjunction with the New York State Newborn Screening Program, and is screening 175,000 newborns. This is the largest newborn screening pilot study in the U.S., backed by $11.3 million in funding from the National Institutes of Health, industry sponsors and patient advocacy groups. It is the hope of the NPC community families, including the Marellas, Andrews and Parseghians, that other families will not have to go through the lengthy, complex journey to find a diagnosis, and that treatments and cures can be accelerated.

“NPC is a brutal disease,” noted Phil Marella. “It impacts neurological and motor functions in young children and is caused by a malfunction in the way the body stores and processes cholesterol. While this disease has impacted our family for 21 years, we have only seen promising progress in treatment options in the past ten years — specifically a clinical trial that our son Andrew is enrolled in that has helped him deal with the devastating impact of the disease.” Andrea Marella added, “This clinical trial and other research into NPC is made possible only through the generous donations of our friends, community and sponsors. Holding the DART to the Finish Charity Walk is our way of doing something fun and raising much-needed funds at the same time.”

To date, DART has raised more than $6 million that has gone toward the search for a better treatment and ultimately a cure for NPC. DART is particularly proud of its commitment as a founding member of a unique, collaborative drug development program called SOAR-NPC or Support Of Accelerated Research. Working with other NPC families and research institutions, SOAR’s collaborators have four clinical trials already to their credit.

To learn more about Dana’s Angels Research Trust (DART) or to register for the DART to the Finish Charity Walk, visit [dartevents.org](http://dartwalk.danasangels.org). To learn more about Dana’s Angels Research Trust (DART), visit [danasangels.org](http://danasangels.org), on Facebook [@danasangels](http://www.facebook.com/danasangels), Instagram [@danasangelsNPC](http://www.instagram.com/danasangelsNPC) and Twitter [@danasangels](http://www.twitter.com/danasangels).

# # #