

Local family to host Peeper Pyper's Party on February 27 to raise funds and awareness for rare genetic disorder

Peeper Pyper's Party is hosted by the Stillman Family and five time Emmy award-winner Mr. Nick Ciletti, to raise funds and awareness for the FD Foundation.

PHOENIX, AZ, UNITED STATES, February 8, 2022 /EINPresswire.com/ -- In honor of their daughter Pyper, the Stillman Family presents their inaugural Peeper Pyper's Party, taking place at the Arizona Jewish Historical Society on Sunday, February 27, 2022 to raise funds and awareness for the [Familial Dysautonomia Foundation](#).

Pyper was born with a rare, disabling, Jewish genetic disorder called Familial Dysautonomia (FD). FD affects the autonomic and sensory nervous systems, which control voluntary and involuntary bodily functions such as:

- blood pressure regulation • temperature control • breathing • swallowing • muscle control
- kidney functions • production of tears • awareness of pain • and much more

While the disorder is extremely rare - Pyper is the 712th person in the world who has ever been diagnosed with this condition - the genetic mutation is not, and can be found in 1:30 Jewish people of Ashkenazic descent.

The prognosis of this disease has historically been very grim. In 1990, a child born with FD had a 50% chance of living to the age of 5; however, the phenomenal teams at the NYU Dysautonomia Center and Familial Dysautonomia Foundation are changing these statistics.

"At 7 years old, Pyper is not only living, but she is thriving! Thanks to the many advances in medical care, children born with FD today have a 50% chance of living to 40, but our goal is to shatter this expectation and give children with FD a 100% chance of living a full life with minimal complications from FD." – Stephanie Stillman, Pyper's mom.

The event is open to all, hosted by five-time Emmy award-winner Mr. Nick Ciletti, Morning Anchor at ABC15 Arizona, and will feature a Scavenger Hunt (led by OAC Experience), Live DJ (Rai Verma), Bouncy House, Pony Rides, Food trucks (Kona Ice, Wiener Wagon) and other treats, a Mimosa bar for the grown-ups, Live and Silent Auctions (Auctions by Subyn) featuring amazing and unique prizes. [Visit https://p2p.onecause.com/pyperparty/home](https://p2p.onecause.com/pyperparty/home) to learn more, register or

donate.

Our goal is to raise \$180,000 through sponsorships, ticket sales, a silent auction and donations.

Information about genetic testing will also be available at the event.

February 28, 2022 is Rare Disease Day, a day to raise awareness for rare diseases and improve access to treatment and medical representation for individuals living with rare diseases.

The Familial Dysautonomia Foundation is a nonprofit organization supporting the best possible medical care and scientific research for the benefit of people afflicted with Familial Dysautonomia. The Foundation also conducts social service and public awareness programs for the benefit of the FD community and for those in the general population who may be at risk for FD.

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