



Charcot-Marie-Tooth Association

MEDIA ALERT

Eight-Year Old with Little-Known Disease Rallies Community to Help Find Cure *GCC's Rock 'n Run for CMT Research 5K Race and Family Festival, Sunday, June 28*

- WHO:** Eight-year-old Grace Caldarone of Kingston, R.I., suffers from a debilitating neuromuscular disease called Charcot-Marie-Tooth or CMT
- WHAT:** GCC's Rock 'n Run for CMT Research 5K Race and Family Festival
- WHEN:** Sunday, June 28, 2009, 10 am to 5 pm; 5K Check-in/Registration begins at 8:30 a.m.
- WHERE:** Ninigret Park, Route 1, Old Post Road, Charlestown, R.I.
- WHY:** Community members will participate in the 5K and family festival to help raise funds for CMT research.

Available for interviews:

- Marybeth Caldarone – Grace's Mother
- Tonia Hassel – Family Friend and Event Organizer
- David M. Hall – CEO, Charcot-Marie-Tooth Association
- Pat Dreibelbis – Medical Liaison and Patient Services, Charcot-Marie-Tooth Association

Photo Opportunities: Grace and wheelchair-bound Marybeth Caldarone supported by family, friends and community members at Ninigret Park.

Kingston, R.I. – June 22, 2009 – Grace Caldarone, an eight-year-old from Kingston, suffers from Charcot-Marie-Tooth, an inherited neuromuscular disease that has confined her mother to a wheelchair.

Affecting an estimated 2.6 million people, CMT is the most commonly inherited peripheral neuropathy. The disease causes a gradual loss of normal use of feet/legs and hands/arms, but recent advances in molecular genetics have created an extraordinary window of opportunity to find a therapy or cure.

In 2007, the Caldarone family began raising funds to support the Charcot-Marie-Tooth Association's Strategy to Accelerate Research (STAR), an initiative that will build on these advances and is expected to develop effective therapies for the most common forms of CMT within three to five years.

For additional information about Grace and the Rock 'n Run, visit www.cmtausa.org/Grace. For more on CMT research visit www.charcot-marie-tooth.org/STAR or contact:

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