Subject: [Reporter’s First Name]: [Your City] Family Spreads Awareness about Rare Genetic Syndrome

Hi [Reporter’s First Name]:

What would you do if your pediatrician told you that your newborn baby would never walk, talk or smile, may need to be institutionalized…and was wrong?

Each year this happens to dozens of families whose children are diagnosed with Cri du Chat Syndrome, a rare genetic disorder that affects only one in 50,000 newborns.

Beginning on May 13, as part of International Cri du Chat Awareness week, [Your City] resident [Your Name] is spreading awareness about the Syndrome. [Your Last Name]’s [age] year old daughter, [CDC Child’s First Name], was diagnosed with the syndrome in [date] and is a patient of Dr. [Your Doctor’s Name] at [Medical Group Name] in [City].

[Your Name] can be reached at [Your Email] or [Your Phone].

French for “cry of the cat”, the syndrome is named for the distinctive kitten-like sound that newborns affected by the syndrome make when they cry. According to [your last name], because Cri du Chat is so rare and pregnancies are frequently normal, the syndrome frequently goes undiagnosed. Children end up suffering from unexplained health issues and developmental delays, often for prolonged periods of time.

Even when diagnosed, doctors continue to distribute outdated information to parents - from a time when children were institutionalized and the outlook was bleak. This is no longer the case.

Starting on May 13, 2012, the 5p- Society, the U.S. based support group for caretakers of people with Cri du Chat, is co-sponsoring the first annual International Cri du Chat Awareness Week. According to [Your Last Name], the goal of Awareness week is to share the most up-to-date diagnosis and care information about the syndrome to as many healthcare professionals as possible, in particular, pediatricians, OBGYN doctors and maternity ward nurses who are the first line of defense when it comes to diagnosis.

[Your Last name] is working with [your medical group name] and is coordinating a social media campaign to spread current information about Cri du Chat to area healthcare providers.

About the 5p- Society

The 5p- Society is the sponsor of the First Annual International Cri du Chat Awareness Week. The Society encourages and facilitates communication throughout the Cru du Chat community and spreads awareness and education about the syndrome and treatment best practices for those affected by Cri du Chat Syndrome. Director, Laura Castillo, is also available for interview or comment.
[Your name] can be reached at [your email address] or [Your phone number]. www.fivepminus.org

More information can be found in the attached press release.

[DON'T FORGET TO ATTACH A COPY OF THE PRESS RELEASE TO THE EMAIL – PDF VERSION IS BEST]