For Immediate Release

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**Change the World by Being You: Cri du Chat Syndrome Awareness**

**Join the 5p- Society and help bring awareness to a Rare Genetic Syndrome**

May 1-10, 2020: International Cri du Chat Syndrome Week, May 1-10

May 5: Cri du Chat Syndrome Day.

The 5p- Society of North America, along with families and support organizations from over 95 countries, are bringing awareness of Cri du Chat Syndrome (CdCS), also known as 5p- Syndrome, a permanent deletion on the “p” arm of the 5th chromosome. The 2020 awareness campaign will showcase videos from around the world focusing on “How an individual with Cri du Chat Syndrome impacts their Community”. Many families and countries world-wide are also hosting 5k events to help with their own awareness campaigns. Join us in celebrating these unique individuals by raising awareness around the world.

The 5p- Society’s mission is to maximize quality of life of individuals with 5p- and their families. One way to improve the lives of individuals with the syndrome is by creating more programs that bring families together. The 5p- Society is sponsoring five Regional Family Get-Together’s throughout the United States and Canada. These one day FREE events create a forever bond with parents who have felt alone in the journey of raising a child with the syndrome. The 5p- Society encourages families to focus on what the individual with the syndrome CAN DO; SEE the PERSON, not the disability; and to PAY FORWARD and educate others on what they have learned about the syndrome and their loved one.

[PERSONALIZE THIS AREA WITH YOUR OWN STORY]

“What I’ve learned about having a daughter with the syndrome (now 32-years-old) is that she is who she is. She doesn’t know of any other path she was supposed to take. She is on the only path she knows and is comfortable being who she has become.’ Says Laura Castillo, Executive Director. “My daughter exuberates joy, she is always smiling, connecting with people and will engage them in conversations about what they are wearing, their pets, or their shoes.” She continues, “Currently we are working with Cri du Chat Syndrome organizations around the world to strengthen our community and drive research on the topics that are most relevant: behavior, speech and language and education.”

“I encourage you to take part in the Virtual 5K, post educational posts on social media, pass out some fliers to your local hospital, and wear your striped socks and your 5p- gear.”  Says Nick Wallace, President of the 5p- Society. “The only way to stop people from being given antiquated information and for families to not be left unconnected is for us to make our voices heard.” Nick encourages families to be bold, reach out and connect families to one another, especially through social media.

In an ongoing effort to raise awareness, members and supporters are encouraged to participate in events throughout the week.

\* Stripy Sock Campaign: Wear striped socks, one long, one short, representing the whole and deleted fifth chromosomes, especially on May 5th. #stripysocks

\* Virtual 5k for 5p-, to raise awareness and money for programs that benefit the Cri du Chat Syndrome community. A Virtual Walk can be anything you want it to be, a walk, a run, a picnic, or any type of event. Over 50 “Teams” have been created all over the world. #5pminus5k. With one team in North Carolina, Graham’s Gang having over 200 participants.

\* Where in the World is C5? In an effort to encourage worldwide participation, we are asking families to pose for a picture with C5, the mascot of International Cri du Chat Awareness Week (named C5 for Chromosome 5) and share their picture on social media using the #SeeC5 and #criduchatawareness. Looking forward to seeing pictures from around the world and maybe even with a celebrity or two!

\* State Proclamations have been applied for and received from several state Governors around the USA.

\* Meet up with other families for a day at the park, or attend a 5p- Society sponsored Regional Get-Together.

For more event ideas, please visit <https://fivepminus.org/event/awareness-week-events/?event_date=2020-05-01>

About Cri du Chat Syndrome: Identified in 1963 by Jerome Lejuene, a French physician, 2020 marks the 57th year since its discovery. Each year in the United States, approximately 50-60 children are born with 5p- Syndrome. It is characterized at birth by a high-pitched, “cat-like cry” caused by an underdeveloped larynx and weak breath support. Other characteristics include low birth weight, poor muscle tone, microcephaly and potential medical complications. The severity of the disorder varies among individuals and can be considered a spectrum disorder. Symptoms go from mild and unnoticed, which causes a delay in diagnosis, to severe where the individual requires to be cared for 24/7 and will require ongoing support from a team of parents, therapists, medical professionals, educational professionals and extended family members to help the individual achieve his or her maximum potential.

About the 5p- Society: The 5p- Society was founded in 1986. It is a non-profit organization that works to empower families with knowledge about the syndrome, facilitate connections, support research, advocate for improved prognosis and to enrich the lives of individuals affected by Cri du Chat Syndrome and their families.

Visit us on the web at http://www.fivepminus.org, @5pminus, #stripysocks #criduchatawareness, #5pminus5k #CDCS #5pminus #SeeC5