

For Immediate Release

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## **May is 5p- Syndrome (Cri du Chat) Awareness Month**

**Celebrating the awesome and unique individuals with 5p- Syndrome all month long!**

May 2024: International Chromosome 5p Deletion Syndrome Month

May 5: 5p Deletion Syndrome Day.

The 5p- Society of North America, along with families and support organizations from over 95 countries, are bringing awareness of 5p Deletion Syndrome also known as 5p Minus (5p-) Syndrome. Over sixty (60) years ago, Dr. Jerome Lejeune discovered this genetic condition by noticing a similar characteristic in several patients that he had been observing of a high pitched “cat-like sound” vocalization. After doing genetic testing on these patients, he realized the connection is caused by a permanent deletion on the “p” arm of the 5th chromosome. The 2024 awareness campaign celebrates these unique individuals by raising awareness around the world through education and community events, such the “Faces of 5p-” campaign, our “Stripy Socks” campaign, as well as a “Virtual 5K for 5p-” event and family regional gatherings.

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 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. Mini Family Meetups have been very successful where families from various states were able to meet, network, establish new friendships, but most importantly know they are not alone in this journey of raising an individual with the syndrome.

“5p- Syndrome is a spectrum disorder. Although there are several similarities between the individuals who are born with the syndrome, each individual is unique” says Laura Castillo, Executive Director of the 5p- Society. “There can be ten individuals with the syndrome in a room, all with the same breakpoint on the p arm of the 5<sup>th</sup> chromosome and each one of them will be functioning at a different level. Some will be functioning at the high end of the spectrum and others at the low end and everywhere in between. We have adults who are living independently and adults who need 24/7 care and assistance.” “The first few years are tough, but then you, as a parent or caregiver realize that they are who they are. Let’s just nurture and guide them so they can reach their fullest potential. Love them for who they are, their strengths and weaknesses, their perseverance, their love for life, their joy and their happiness.”

“I encourage you to create and/or take part in a Virtual 5K, post educational posts on social media, and wear your striped socks and your 5p- gear.” Says Nick Wallace, President of the 5p- Society. Nick challenges the 5p- community to 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 month.

- \* Stripy Sock Campaign: Wear striped socks, one long, one short, representing the whole and deleted fifth chromosomes, especially on May 5th. #stripysocks
- \* Face of 5p- Campaign – We will soon be flooding our Social Media pages with pictures and bios of our children and adults with 5p- during awareness week and beyond. Learn a little more about each of our kiddos and how truly awesome they are.
- \* Virtual 5k for 5p-, to raise awareness and money for programs that benefit the 5p Deletion Syndrome community. A Virtual Walk can be anything you want it to be, a walk, a run, a STAY HOME picnic, or any type of event. Over 50 “Teams” have been created all over the world. #5pminus5k. Some families have postponed their events until they can safely have them in their communities.
- \* 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 5p Deletion Syndrome Awareness Week (named C5 for Chromosome 5) and share their picture on social media using the #SeeC5 and #cri duchatawareness. 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.
- \* 5p- Society office in Lakewood, California will be hosting a Family Regional Gathering including a 5k for 5p-, baseball/softball and kickball games along with other lawn games and of course food and beverages. All are welcome to join us and to celebrate the beautiful individuals with 5p- Syndrome. Event will be held Sunday, May 5, 2024 from 1pm to 4pm at San Martin Park, Lakewood, California. Contact Laura Castillo at 562-756-4123 for more information.

For more event ideas, please visit <https://fivepminus.org/event/awareness-week-events/>

About 5p Deletion Syndrome: Identified in 1963 by Jerome Lejuene, a French physician, 2023 marks the 60th year since its discovery. Each year, approximately 50-60 children are born with 5p- Syndrome worldwide. It is often characterized at birth by a high-pitched, “cat-like cry” caused by an underdeveloped larynx and weak breath support. For this reason, it was previously called “Cri du Chat” or “Cry of Cat” Syndrome. We have since learned that the syndrome may be misdiagnosed early on due to the absence of this characteristic; hence our emphasis on the more medically accurate name of 5p Deletion or 5p- Syndrome.

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 5p- Syndrome and their families.

Visit us on the web at <http://www.fivepminus.org>, @5pminus, #stripysocks #5pawareness #5pminus5k #5pminus #SeeC5 #Facesof5p