



EMPOWER ME

A NEWSLETTER FROM THE 5P- SOCIETY

VOLUME 39, ISSUE 1 2024

AWARENESS MONTH

EACH YEAR THE 5P- SOCIETY PROMOTES A WEEK OF INTERNATIONAL AWARENESS OF 5P- SYNDROME, OR CRI DU CHAT. STARTING IN 2024 WE WILL CELEBRATE ALL MONTH LONG. THE PURPOSE OF THIS EVENT IS TO RAISE AWARENESS AND ENCOURAGE SUPPORT OF THOSE WITH THE SYNDROME. IT ALSO MARKS THE 61ST YEAR OF THE FINDING OF CRI DU CHAT SYNDROME BY DR. JERMONE LEJEUNE



INTERNATIONAL 5P- SYNDROME AWARENESS DAY IS MAY 5TH.

FOR MORE INFORMATION ABOUT AWARENESS WEEK OR THE VIRTUAL 5K FOR 5P- GO TO

[HTTPS://FIVEPMINUS.ORG/EVENT/AWARENESS-WEEK-EVENTS/](https://fivepminus.org/event/awareness-week-events/)

VIRTUAL 5K FOR 5P-

Announcing the 9th Annual Virtual 5k for 5p- benefiting 5p- Society to be held during International 5p- Syndrome Awareness Month of May 2024. This is so much fun and can be done on any day, time or place you choose during awareness week. For more information and to register your team online go to the [website](#) listed above.





FACES OF 5P-

This year we will be featuring your kiddos on their own Trading Card as an MVP of the C5 Sluggers. Start thinking about what you'd like to HIGHLIGHT about your loved one with 5p- syndrome. for more information go to <https://fivepminus.org/event/awareness-week-events/>

2024 DES MOINES 5P- SOCIETY FAMILY CONFERENCE JULY 25-28, 2024

Join us in Des Moines, Iowa for this years' annual conference. Our host families have been hard at work creating an amazing conference for us all to enjoy. A few things to look forward too

- Family outing will be an emersive activity onsite
- The siblings will travel to a virtual reality gaming room

Visit the website for more information and to register.If you'd like to help the host families raise funds for the conference you can get rewarded for the amount you raise.

<https://fivepminus.org/event/2024-des-moines-5p-society-conference/>

THE NEWSLETTER HAS A NEW LOOK. IF THERE IS SOMETHING YOU WANT TO SEE IN FUTURE NEWSLETTERS LET US KNOW!

MMYATT5PMINUSSOCIETY@GMAIL.COM



LOOKING FOR SOME 5P- GEAR FOR AWARENESS WEEK?

VISIT OUR SQUARE SHOP

Who is doing Research?

The Cri du Chat Research Foundation(CDCRF), is a non-profit organization dedicated to developing therapeutics for 5p minus syndrome. They have launched a data collection platform through Simon Searchlight to collect details on 5p minus syndrome from individuals living with diagnosis. Their hope is to develop a Natural History Study (NHS), or a long-term collection of data. This would prove useful to advance potential therapies and drug trials for patients with cri-du-chat. For more information or to get involved, go to their website at criduchatresearch.org.



5pRA is a non-profit organization with the mission of fueling research on 5p- genetic disorders to better the lives of impacted individuals. By providing research grants to qualified researchers and clinicians, 5pRA strives to support the development of treatments for 5p- individuals.

Learn more about their research initiatives at:
<https://5pra.org/>

SIMONS SEARCHLIGHT

Simons Searchlight is an international research program with the goal of accelerating science and improving lives for people with rare genetic neurodevelopmental disorders. They maintain a database over 175 rare genetic neurodevelopmental disorders. If you would like to find out more or even want to participate, go to <https://www.simonssearchlight.org>

“Most see what is
and never what can be”
-Albert Einstein

“Some of the most
wonderful people are the
ones who do not fit into
boxes”
-Tori Amos

BY ACCESSING RESOURCES PROVIDED BY THE 5P SOCIETY, MEMBERS ACKNOWLEDGE AND AGREE THAT THESE RESOURCES ARE FOR INFORMATIONAL PURPOSES ONLY. THE SOCIETY DOES NOT PROVIDE LEGAL, FINANCIAL, OR PROFESSIONAL ADVICE. MEMBERS ARE ENCOURAGED TO SEEK APPROPRIATE COUNSEL FOR THEIR INDIVIDUAL NEEDS AND CIRCUMSTANCES. THE SOCIETY DISCLAIMS ANY LIABILITY FOR ACTIONS TAKEN BASED ON INFORMATION OBTAINED FROM ITS RESOURCES.