

PERTHES BRIEF December 2019

Here is the latest news from Perthes Kids Foundation...

 Happy Holidays from Perthes Kids Foundation! We were so happy to team up with <u>Rare Science</u> to deliver special Rare Bears to Perthes Kids around the world! (If you haven't received yours yet, don't worry... deliveries will be from now until the end of January.) When you receive your bear, please post it on social media, tag Perthes Kids Foundation and tell us where you live. We want to raise as much #PerthesAwareness as possible for this one-of-a-kind gift and PKF global promotion!



• Don't forget, if you shop on Amazon this holiday season, **AmazonSmile** will donate 0.5% of your purchases to Perthes Kids Foundation. You can learn more at https://smile.amazon.com.



• **Perthes Kids Foundation** often speaks with doctors/clinicians to help them better understand what living with Perthes disease is like and how to better treat the *patient*, not just the condition. For those parents/adults dealing with Perthes that had trouble finding doctors who have heard of LCPD and/or understand what you are going through after receiving such a diagnosis, this **Global Genes** program could prove helpful in educating



young medical professionals as they progress in their careers. The **RARE Compassion Project** matches eligible medical students with a rare disease patient or family, giving them an opportunity to learn firsthand about a diagnosis as well as the unique challenges faced by patients every day. Sharing your Perthes story, as a patient or caregiver, can make a real difference! To learn more, please visit <u>https://globalgenes.org/compassion/</u>.

MEET OUR PERTHES KIDS FOUNDATION GLOBAL AMBASSADORS: We are happy to introduce Claudia Giffuni Pai, volunteer and PKF Global Ambassador from Gainesville, Florida. Originally from Bogotá-Colombia, Claudia moved to the USA in 2002. In May 2009, her son, Nicholas (Nico), was diagnosed with Perthes. During her search for more information, Claudia discovered Perthes Kids
Foundation. In 2013, Claudia's son attended the inaugural Camp Perthes USA and Claudia joined in the effort to raise awareness of LCPD and help other kids like
Nico. Claudia has been a volunteer for the past two years at Camp Perthes USA and since 2018 has managed Perthes Kids Foundation en Español (pertheskids.org/esp & on Instagram @ninos_con_perthes). Her goal is to expand #PerthesAwareness to the Latin community and ensure Spanish-speaking families have access to much needed information and support. In the future, Claudia would love to bring Camp Perthes to Central or South America!

pertheskids.org



