

HEALTHCARE FOR CHILDREN WITH RARE DISEASES

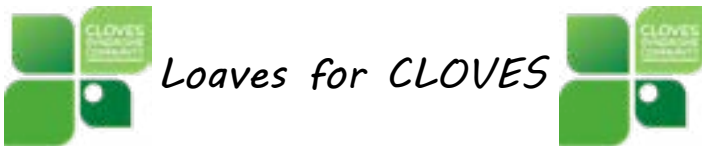
Advocacy Efforts of Robynn Kuhns, Grant Manager

Prepared May 2020 by Evan Daly, 6th Grade



Children's healthcare is a focus of the Hayes Family Foundation. This month, we dedicate our newsletter to CLOVES Syndrome and other rare diseases. Grant Manager Robynn Kuhns's daughter, Ellena, was selected among dozens of nominees to be a Children's Hospital Colorado Patient Ambassador. Ellena has CLOVES, an extremely rare condition that has required multiple surgeries and presents significant medical challenges. Yet, friends of Ellena know she is unstoppable and always has a smile to share!

In just three months, Ellena's Patient Ambassador page raised \$2,445 on behalf of her Vascular Anomaly Clinic physician, Tazio Nakano. Please visit her Patient Ambassador page <http://c-fund.us/pq3> to learn more or to contribute.



Established in 2016 with the sale of a few homemade loaves of bread, Robynn and Ellena elevated their annual Loaves for CLOVES bake sale at Ellena's new middle school. Ellena worked with sixth grade assistant principal, Ms. Frenzel, to run a house fundraising competition on behalf of the [CLOVES Syndrome Community](#). Over several weeks, money was collected from each house with a final "bake off" event scheduled for March 17. The COVID-19 pandemic resulted in school closing days before the final event, but even though the bake off did not occur, Ellena's advocacy raised an estimated \$1,000. Way to go Ellena!

Traditionally, the Hayes Family Foundation has matched the amount raised by Loaves for CLOVES. This year, after attending the 2019 biannual CLOVES Syndrome Community Family Conference in Boston, Robynn recommended a designated grant for their inaugural Betsy's Camp. In honor of Betsy's legacy in education (she was a teacher in Colorado), the small summer camp was growing to support up to twelve families. Shortly after the grant was awarded, [Betsy's Camp](#) was cancelled due to COVID-19. With Robynn's encouragement, the funds were reallocated to assist families financially impacted by the COVID-19 pandemic.

Colorado Rare Disease Day 2020

On Thursday, February 27, Robynn Kuhns represented the CLOVES Syndrome Community for the first-ever event for Rare Disease Day at the Colorado State Capital. Sponsored by Colorado Rare Action Network with volunteer state ambassador Nick Kirchof acting as liaison between his personal story and his professional lobbyist career, a unified voice "Alone We Are Rare. Together We Are Strong" emerged.



Only an estimated 300 people have been diagnosed with CLOVES. Rare disease is defined as conditions, disorders, or illness impacting less than 200,000 people. Collectively, over 25 million Americans are impacted by one of over 7,000 rare diseases, yet more than 90% of rare diseases do not have an FDA-approved treatment. With a detailed display sharing the complexity of CLOVES to state legislatures and fellow advocates, Robynn presented the challenges of living with CLOVES and the complicated journey of understanding treatments and medical advancements. (Continued on Page 2.)

A parent advocate for her adult child with VACTERL (the congenital rare condition Lindsey Hayes Daly's daughter, Clare, fought in her first year of life) shared the frustrating transition from childhood support to the reality of adult-world assistance disappearing. While no set political platform was established, the morning of shared empathy, exasperation, and empowerment inspired future advocacy in Colorado. With strong momentum, magnified by the COVID-19 pandemic, the Hayes Family Foundation's connection to the National Organization for Rare Disorders expanded to solidify our role in burgeoning local efforts. For more information, including individual state's current legislative action on behalf of rare diseases, please visit <https://rareaction.org/>.

In the spirit of supporting rare disease, please join us in the virtual [Petri Dash](#) race June 6-7 to support the Morgan Adams Foundation, a local nonprofit who has supported rare pediatric cancer research since 2001 and, now, the families of kids with cancer who have experienced income loss due to the COVID-19 pandemic to ensure children receive ongoing treatment.



COVID-19 Pandemic: How We Are Responding

First, we inquired with current grantees what assistance was needed. After speaking to friends in the medical community but recognizing that we did not have access to coveted supplies, we contacted Saint Joseph Hospital's long-time funding partner Scott Farley, Director of Major Gifts (who helped us establish the [Diane Holten Scholarship](#)). Based on Scott's knowledge of our giving priorities, his suggestion was to support the [SJH Emergency Fund](#). Our contribution will fund a wide variety of unforeseen challenges specific to Saint Joe's, such as buying more rapid testing capabilities and bringing in more support for both in-house and virtual visits with family members.

We contributed to nonprofits outside our existing grantee portfolio. The Hayes family is a fourth generation Park Hill family, so we wanted to find an organization that provides direct assistance to individuals and families impacted in the Park Hill neighborhood. We asked Andrew Lefkowitz, co-chair of current grantee, [Park Hill Neighbors for Equity in Education](#) what need he saw within the school community. His feeling: we are in a situation of meeting the basic hierarchy of needs. Lana Cordes, Executive Director of the Greater Park Hill Community, Inc., concurred that the [Park Hill Food Bank](#) is "currently serving, on a weekly basis, on average, double the number of households we were serving about a month ago and triple the number of households we were serving at this same time last year at our walk-up pantry." We provided an emergency donation to support Park Hill Food Bank's service to our community.

Additional COVID-19 pandemic donations have included: [Dirt Coffee Bar](#), [Open Door Ministries Te Veo House](#), [Brother's Redevelopment](#), and [Girls Helping Girls. Period.](#) Elise Joy, Co-Founder/Executive Director of GHGP sent this heartfelt thank you:



HAYES FAMILY
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"I have spent some time reading through your family's foundation website and I am so touched at the way you all honor your grandfather. My daughters and I founded Girls Helping Girls. Period. because we also come from a family where community service is just a part of who we are. About ten years ago we lost a beloved great aunt, Ruth, who gave financial support to more than 40 organizations each year. She personifies the spirit of giving in my family and I believe yours holds those same values dear."

Most harrowing during this time are the mental health struggles we are collectively facing. We continue to actively collaborate with existing and new mental health partners during the COVID-19 pandemic and wanted to share Executive Director, Lindsey Hayes Daly's most recent Letter of Reflection: "[Redefining Social Interaction and Impact.](#)" Thank you for your support and stay healthy and well!