Dash 4 DESSH Local Community Fundraiser
By Tyler and Katie Hartung

1) Set a goal. People are driven by goals. Set one that is achievable in your mind for your community.

2) Make the ask specific, and related to a thing that would benefit many kiddos for the long term. While we knew that requesting money for a cell line was not exactly what every dollar would go towards, it was something we knew the foundation was doing, and something tangible like that that has a long-term benefit with something people could get behind. Now, not everyone may have a goal (#1) that can be as big as our initial goal of $8,000 for a new cell line. That's ok. Pick something else! Pick a portion of something. It doesn't matter as long as people know it is going to something great!

3) Share truthfully and vulnerably from the heart. Not just "whoa is me", but a tail of "this is hard, and we are here for it, and we need your help." This is the truth. People respond to vulnerability and truth. See our emails below. The parts that are heartfelt come directly from Katie. A mom who was hurting. Also, the pictures make it personal. This is one of the kids you will help! You know him. Here is his picture. His doctor is real! Here is Rye meeting him. Etc.

4) Make the communication clear, with clear asks. So as you read the emails below, the formatting, the clear headers, the ***clear asks*** with links is all my contribution. So there is the heart portion (#3), but there is the "make it easy to consume and easy to know what to do portion". That is just as important.

Random thought: Remember that rare is an asset. People are supporting the underdog story with our kids and DESSH.

The DESSH Foundation

5) Make it all inclusive - anyone reading the email can take action, even without $'s. We invited people to the event without requiring an ask for money. But we also layered on an ask and a way to give. But the momentum behind the free event helped build the momentum behind the giving. Another way to say this is "make it all inclusive" - anyone can come, even if they cannot give. We had friends invite people we literally did not know. Next thing we knew, a retired pediatrician was there (this person likely donated)! Having action that anyone can take makes more people open and read and engage. Some give, some don't. Also, make it doable beyond your physical location. We had dozens of people literally do a walk and send pictures in other states! Why? B/c we made that a clear way to be involved in the emails. But a movement is built.

6) Invite everyone. And ask them to invite others. Old acquaintances. Old neighbors. Old coworkers. Scroll your facebook friends. Get it out there! The worst they can do is just delete the email. The most likely they will do is read your story. Some will participate. Some will give. These are all wins.

7) Follow Up. Updates along the way (see email #2 below). Hand written thank you cards (Katie). Inspiring Instagram Post (Tyler)

Below you will find some of our communications from last year. We are happy if people want to use some of the text if it helps them! I call it R&D - Rob and Duplicate!

The DESSH Foundation

[Sample Email 1]

Subject: Rise with Rye - Join Us

Dear Family and Friends,

This past spring our lives shifted. Just after turning 1 Rye was diagnosed with an incurable ultra-rare genetic disorder called DeSanto-Shinawi Syndrome (DESSH). Only a few hundred people in the world have been diagnosed with DESSH. When a parent hears that their child has a rare condition the overwhelming uncertainty is perhaps the hardest to bear. There's no clear road map, no proven treatments. As parents we are so hopeful for our child's growth, milestones, and a bright future. But when faced with conditions that have no cure we were left wondering: *Will Rye ever walk, talk, or live independently?* Our grief has had many layers. It's the grief of a future that looks so different from what we imagined, or dreams that may never be realized, and of an uncertain and difficult path ahead.

But our heartbreak has been filled with love - a fierce, unconditional love that is driving us to fight, advocate, do more for Rye even when exhausted, and ultimately fill ourselves with hope! And what we are learning is that our imaginations have left out some of the best parts of what will be Rye's journey - the love, the joy, the compassion, the spirit, and **connection to his community that will make him feel loved, seen, cherished, celebrated, and happy!**

We invite you to walk with us (in person or from afar) in support of Rye - a celebration of his continued strength, resilience, and the power of community. DESSH has made the basics - like walking and talking - a hurdle for Rye. What better way to come together as a community to celebrate our health, our abilities, and our spirit than to join him by walking (and talking) together. Your participation means the world to us, and to all kiddos with DESSH.

Ask #1: Sign Up for the Walk You don't need to be in Denver to participate! Denver folks this will be at Wash Park at 1:30pm on November 10th.

Ask #2: Consider helping us create a new cell line by donating here. We have the goal of raising $8,000 for the DESSH Foundation to cover the cost of creating a DESSH cell line, which is essential for advancing science's understanding and treatment of this ultra-rare genetic disorder for all of those living with DESSH. Since it is so rare, any advancement in knowledge and research has to come from the incredibly small but powerful grassroots effort of the DESSH community. Follow the link to read why this research matters, why cell lines are so expensive to produce, and the long term benefit of creating one.

Together we are strong. Rise with Rye.

With Love, Katie, Tyler, Asher, Easton and Rye

Rye with Dr. Shinawi who identified this genetic disorder and leads work on it. A joyous, brilliant man.

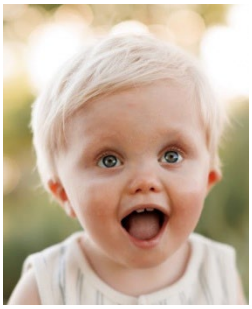
Rye with a Dr. at DESSH Clinic at Washington University in St. Louis. All the doctors at the Clinic volunteered their time.

The DESSH Foundation

[Sample Email 2 - Mid Stream]

Subject: Rise with Rye: Step 1 Accomplished, Let's Keep Rising

Family and friends,



Rye says "Wow! We did it thanks to you!"

Our $8,000 goal was met! We are so honored to have reached this goal to create a new cell line and further the research of DESSH! We are blown away and thankful beyond words!!! ***To those that have already donated, THANK YOU! — although these words don't seem adequate for the gratefulness we have for you all.***

Let's Keep Rising: While we have reached our initial goal, if you feel inclined to continue to support financially, please do so knowing that support goes directly to the *second cell line* and other important efforts of the DESSH Foundation. The foundation had an overarching goal of producing two cell lines, so anything donated over our goal will go towards the second cell line. These funds are still critical and important.

The DESSH Foundation was started and is run by a small but mighty group of volunteer parents. These parents of the early DESSH kiddos asked Dr. Shinawi "So what can we do?" and he told them bluntly, *"You, the few parents, must organize and you must advocate. That is the only way change will happen."* And so these parents, along with their other burdens, did just that. We know these people personally now. Their kiddos' stories are here. These pioneering parents are a small but very mighty group and punch above their weight class. They do their work via the DESSH Foundation to find and support research, organize clinics (like Rye just went to at Washington University in St. Louis) with doctors volunteering their time to advance our knowledge of what can be done for kiddos with DESSH, and advocating in the halls of government for things like more funding and clearer paths forward for research on ultra-rare diseases.

With your help we did it! Let's keep rising!

With heartfelt appreciation and awe,

Katie, Tyler, Asher, Easton, and Rye