Friends & Family,

Happy (late) Thanksgiving & (early) Christmas! My name is Daniel and I have the privilege of being Isaac's daddy. Receiving this letter indicates that you are someone who has already expressed care for our son in some way, and for that we are thankful. Because of your care, we'd like to provide you with an update on Isaac, as well as a plea for your help.

Isaac's Past

As you may know, Isaac's first 2 years of life were pretty harrowing. After discovering swelling on his brain during Mindy's 19-week ultrasound, we started preparing as best we could for the uncertainty of what was to come. Born in October 2011, Isaac weighed just over 3 pounds and needed lots of immediate attention. He underwent several surgeries & tests within the first 24hrs, including a brain shunt and a colostomy. About a month after birth, with Isaac still in the NICU at the Levine's Children Center in Charlotte, we received the bittersweet diagnosis of Isaac's genetic disorder: Fanconi anemia. I say it was bittersweet because, on the one hand, we were relieved to have some answers to all of Isaac's seemingly unrelated issues (missing radius bones & thumbs, fused kidneys, stage III kidney failure, imperforate anus, small optic nerves, severe hearing loss, hydrocephalus, small stature, heart abnormalities). But once we found out what that diagnosis would mean for our son long-term, it was a devastating blow for us as a family and a true test of our faith.

Isaac's Present

Fast forward to now, 10 surgeries and countless follow-ups & therapies later. Isaac is a happy, lively little boy who daily lives up to his name's biblical meaning of "laughter." He just celebrated his 3rd birthday with a superhero party. He knows hundreds of words, talking about everything from his all-time favorite animal (walrus) to letting us know when his bone-conduction hearing aid needs the batteries changed. Even though Isaac still weighs just 14 pounds, he's getting closer and closer to walking on his own, which is amazing considering he never crawled! He just started attending his first preschool class in November, in which he learns alongside several other hearing-

impaired children for a couple hours a week. Isaac loves getting out and interacting with other kids, whether it's at our church, at Discovery Place Kids just a block down the street, or at our library's weekly story time. He's also very musical and is always scooting over to our record player to listen to Mary Poppins, Winnie the Pooh, Raffi or his "Jesus songs," as he calls them.

These things may seem small & ordinary, but to us, they are HUGE. Isaac's diagnosis is so rare and so variable that we really didn't know what to expect for him developmentally. But to have this smart, handsome, energetic little boy in our home for 3 years is something we thank God for as often as we can. It's easy to take the time we've had with him for granted, so Mindy and I are learning how to better seize each day and do everything we can to provide a long, meaningful life for our son.

Isaac's Future

As much as I'd like to end this letter here and say everything is behind us, it's not. Frankly, Isaac's future is not bright, and this is why I'm writing to you now. Although he appears to be healthy and has made it through his early battles like a true fighter, his years ahead will be his toughest. Despite what you can see of Isaac's disease on the outside, Fanconi anemia is first and foremost a genetic *blood* disorder. Basically, Isaac has very weak blood that will eventually fail, usually during the later childhood years. He will require a risky bone marrow transplant to totally reset his blood system. And even if he's able to get an adequate genetic match (preliminary searches were less than encouraging) and the transplant is successful, he'll face many challenges for the rest of his life. Statistically, Fanconi anemia patients are fortunate to survive into their 30's, due to both the complications of the transplant procedure itself and the extremely high susceptibility to cancer post-transplant.

So today, on behalf of my son, I'm asking you to consider supporting the Fanconi Anemia Research Fund (FARF). Not only is this organization our best hope at finding a cure for Isaac's disease, but it has been a constant source of encouragement and support for our family. They've been by our side every step of this journey and we thank God for the work they've already done to give families like ours a little bit more hope for our kids' futures. Any gift you're able to give towards the furthering of this work would mean so much to us. Thank you for your love for Isaac!

About FARF

Founded in 1989, the mission of the Fanconi Anemia Research Fund is to find effective treatments and a cure for Fanconi Anemia and to provide education and support to affected families worldwide.

- *Funded $700k in new grants in 2014, supporting research of FA cell protectors, genetic therapy, early cancer detection, DNA repair and other relevant areas*
- *Hosted 23rd annual FA Family Meeting in Maine (57 families, 11 first-timers)*
- *Hosted 26th annual Scientific Symposium (210 scientists from 17 countries)*
- *97% of funds come from fundraising of affected families, with 88 cents of every dollar going directly to research/support*
- *Received highest 4-star rating from Charity Navigator (2012)*

Ways To Give

- ❑ *Online: Fanconi.org*
  (Designate to Isaac Coleman)
- ❑ *Check: Fanconi Anemia Research Fund*
  1801 Willamette Street, Suite 200
  Eugene, OR 97401
- ❑ *Phone: 1-888-FANCONI*