DATE

[Brief history of when concerns over your child’s health began].  This marked the beginning of a journey much longer than we could have predicted.

(Child’s name) was just (age of child during events described above) then.  Today, s/he's a beautiful (child’s current age).  S/he's had more labs drawn over the past (insert period of time here) than we have had in our lifetimes combined.

(Child’s name) was recently diagnosed with something called Shwachman-Diamond Syndrome caused by a rare autosomal genetic mutation.  While his/her diagnosis helps us to better understand his/her previous medical problems, the news is quite difficult to process.   
  
It’s estimated that 1:75,000 live births have Shwachman-Diamond Syndrome. That would mean about 55 newborns in the U.S. this year will have SDS. To give you some context, our local children’s hospital has about ## new cancer patients each year. They receive a new Shwachman-Diamond patient about ##.  It is an inherited, multi-system disorder which affects the pancreas, bone marrow, skeleton, and may affect other organs.  Children with SDS can be frequently and severely ill with infections that can be life-threatening.  S/he is at a higher risk of developing leukemia, bone marrow failure, and potentially fatal blood diseases.

We have no way of knowing when this will take a turn or how rapidly (Child’s name’s) health will deteriorate once it does.  What we do know is that if s/he comes down with a fever, we've been advised to pack our bags and head to the ER.

Medical scientists cannot say with certainty what the long term future holds for (Child’s name).  The median life expectancy of this condition is more than 35 years.  With complications, it could be less.

If you are looking for a way to help, please consider joining the Shwachman-Diamond Syndrome Research Fund. This nonprofit will help you set-up a fundraiser, big or small, to boost the funding going to research on this rare condition. Funds to support these researchers are just as rare as the condition itself so every little bit counts.

We're very optimistic that (Child’s name) will live a long life; s/he’s in good hands.  The specialists we are working with are so smart and taking this very seriously.  They are coordinating his/her care and will be monitoring him/her closely.  We feel confident that by staying on top of this, s/he will be able to lead a happy and long life. God Bless them. 

Please don't pity us or feel bad for us.  We are so blessed to have such an amazing and special little boy/girl who has made our hearts whole.  Please pray for us and pray for (Child’s name).  S/he is strong.  S/he has the spirit of a fighter and we couldn't be more proud.

Sincerely,

(Your Name), (Spouse’s Name), and (Child’s name)