



# Shwachman-Diamond Syndrome Foundation

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Dear Families

I'm sure we are all aware that the World Health Organization has now declared the Coronavirus a pandemic. Like everyone else, we are listening to all the information being passed on by WHO and the CDC. We have and will continue to post safety precautions on our Facebook pages.

We strongly suggest that you follow strict neutropenic precautions. What is a new concept to many families at this time, is something that we have been doing as part of our regular routines for quite some time. Handwashing, not touching faces, coughing into elbows are all common sense measures. In addition, sanitizing hard surfaces, especially door knobs/handles, removing shoes, and washing hands immediately upon return from activities/work are great practices. We recommend that you limit outside activities and restrict visitors as is often the case during virus season. None of the WHO or CDC recommendations are new to us.

I think SDS parents are very smart and well educated about what it takes to keep your child as healthy as possible. This is definitely the time to put all that knowledge into practice.

If you feel you need to pull your child from school, please do. Many school systems across the country have started moving to remote education in the past few days, so this may be less disruptive than was thought even a few days ago. Reach out to your child's school and find out what is their plan. Start to prepare for a period of 'homeschooling' even if your child has been able to attend outside schools. Just because they are at home doesn't mean learning needs to stop!

Please contact your primary doctors. Know what they are recommending for your child's particular case. Know when you NEED to take your child in for evaluation and know what you can handle at home. If you have already done so, you might touch base again as this situation changes to be sure that you are all still on the same page and have all of your doctors current recommendations.

Make a plan of action BEFORE someone gets sick. Know who you will need to call to help with other children. Have a bag packed with those extra items that often get forgotten when you have to leave quickly for a hospital visit, include activities for your child, chargers for your phone/tablet, personal hygiene items. Even an extra gift card for meals if needed. Dice games can be fun and dice are easy to clean. Waterproof decks of cards are also easy to clean and sanitize.

Remember, this is your family to keep safe! Other's opinions that you are going overboard are irrelevant. You have been living this life. You know your child. You can do this! We, as our SDS community are all in this together. You are not alone. Together we are **SDStrong!**

*Joan Mowery, President SDSF*

Member of:  
National Organization for Rare Disorders (NORD)  
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