

Shwachman-Diamond Syndrome Foundation

IDEAS FOR A FUNDRAISING LETTER

- 1. Start with a very personal statement.** A plea for help, and a brief description of your child's situation. Some examples follow:

- A. "This is a letter I hoped I would never have to write and I am sure you would never want to receive. However, I must! I hope you will read it and do whatever you can to help.

We have a wonderful and loving grandson, (insert name), now (insert age). He is afflicted with a rare disease called Shwachman-Diamond Syndrome. Words can never express our sadness and devastation..."

- B. "We would like to thank you for your support since our son (insert name) was diagnosed with Shwachman-Diamond Syndrome three years ago.

A few weeks ago, a friend in California asked how her/his health was. He then said, "I feel so helpless. I wish there was something I could do." We told him he can help and make a big difference – not only for our child, but to the many others who suffer from Shwachman-Diamond Syndrome."

- C. "As you probably know, our beloved child (insert name) is in need of a bone marrow transplant to correct immediate life threatening complications from Shwachman-Diamond Syndrome. It is difficult for us to describe the horrors of this diagnosis. We have watched in agony and despair the downward course of his/her illness.

Medical scientists cannot say with certainty what the long term future holds for our child. I hate to ask for help, so I have put this off for some time. But my desperate sense of urgency has overcome my reluctance and I am turning to my friends and family for help..."

- D. "As many of you already know, in April we learned that our three year old son/daughter, (insert name) has a rare genetic disease called Shwachman-Diamond Syndrome. While his/her diagnosis gives us new insight into his/her previous medical problems, the news has been devastating..."

- E. "Some time ago you responded generously to our appeal for help. I cannot tell you how grateful we were. I want to report that there has been no spectacular progress and ask for your financial help again..."

2. Describe, briefly, what Shwachman-Diamond Syndrome is:

- A. "Shwachman-Diamond Syndrome is a mysterious and often fatal disease..."
- B. "Shwachman-Diamond Syndrome is an inherited, multi-system disorder which affects the pancreas, bone marrow, skeleton, and may affect other organs..."
- C. "These children can be frequently and severely ill with infections that can be life threatening. Patients with Shwachman-Diamond Syndrome are at a higher risk of developing leukemia, bone marrow failure, and other potentially fatal blood diseases..."

3. Describe the tremendous progress being made in research, our reasons for hope, our need for their financial support.

"Dr. Tarek Elghetany, Department of Hematopathology at the University of Texas, Medical Branch, Galveston, Texas, is studying the bone marrow and blood of patients with Shwachman-Diamond Syndrome for early signs of myelodysplastic syndrome and leukemia."

"Ongoing research projects led by Peter Durie, MD, Melvin Freedman, MD and Johanna Rommens, PhD, are taking place at the Hospital for Sick Children. Information and patient samples are being recruited to survey and test bone marrow and exocrine pancreatic dysfunction. Genetic studies are also being done for molecular genetic studies geared toward tracking the chromosomal defects in order to achieve improvement in diagnosis and care of patients."

"Dr. Peter Durie's group at the Hospital for Sick Children (HSC) in Toronto are undertaking a research study to examine whether there is a generalized defect of acinar cells in SDS."

"Funds to support these researchers are in critically short supply. This is why we are asking family and friends for help. If sufficient support is available, researchers are confident that they will make significant progress over a period of 3-5 years. Your contribution is vital to this research."

"But much remains to be done. We need to support research which will prolong lives, while we push for a cure for Shwachman-Diamond Syndrome. These researchers desperately need our help!"

"We are turning to our relatives and friends for help. Can you give \$25, \$50, \$100, \$250, or even \$1,000 for this vital cause?"

"Your check should be made out to Shwachman-Diamond Syndrome Foundation. It can be mailed to us and we will forward it or you can mail it directly to the following address: P. O. Box 40, Avon, NY 14414."

4. Consider adding more personal information about your child at the end of your letter.

Repeat your plea for help:

“Johnny is a bright, happy, well-adjusted eight year old. He is currently in the second grade and loves school, Nintendo, and the Cincinnati Reds. We are including his picture so you can see what a spunky kid he is!”

“Susie’s enthusiasm for life touches all who meet her. Her compassion for her friends makes her popular and respected by her peers.”

“Watching Johnny and his sister Stacy, age five, play every day, you would never guess one of them might not have a chance to lead a full and productive life.”

“We have no way to know when this tragic disease will strike Peggy hard. We have no way of knowing how rapidly Peggy’s health will deteriorate once it does strike.”

“We can only hope, pray, and do our share to speed the research efforts as they race to find a cause and a cure.”

“We thank you for your concern and your prayers. There is nothing more important to us than the lives of our children. We know you will agree.”

“We are asking for your help. Please send a contribution today. Your gift could be the difference, not only for Billy, but for many others like him.”

“Our deepest and sincerest thanks.”

5. Always add a P.S.:

P.S. Again thanks for your contribution. We can never adequately express our gratitude for knowing that we can count on your help.

P.S. You may get many requests for help. But please know that this cause will help save lives.

P.S. Please keep the picture of Julie as a reminder, each day, that your contribution could make a real difference in giving her and many others the chance for a bright future.

6. A short, handwritten note at the bottom of your letter is extremely effective. Something like this:

“This cause means so much to us-Please help if you can.”