

SAMPLE GRANT REQUEST LETTER

Dear _____:

I am writing to ask for your financial assistance in providing travel and conference funding so that I (*or my family and I*) may attend the **CHARGE Syndrome Foundation Conference, July 27-30, 2017 in Orlando, Florida.**

I (*or my son/daughter*) was born with CHARGE Syndrome. CHARGE syndrome is a recognizable (genetic) pattern of birth defects, which occurs in about one in every 9,000-10,000 births worldwide. It is an extremely complex syndrome, involving extensive medical and physical difficulties that differ from child to child. In our case, CHARGE has affected me (*my child*) in the following ways. (*Insert a description of the physical, behavioral, educational challenges encountered and what you/your child have done to overcome them*). (*Hint: try to focus on the positive things & not the negative. You aren't asking for sympathy here; you are asking for funding to help you do one more positive thing related to CHARGE.*)

Because the syndrome is so rare, the CHARGE families are often widely dispersed in each state and most only have an opportunity to meet at these conferences. We also have the opportunity to learn from a wide range of professionals from all over the world who are knowledgeable about CHARGE syndrome and its medical, educational, social, and developmental challenges. For most people diagnosed with CHARGE, the conference represents their only opportunity to interact with peers who cope with similar challenges.

Further, this conference is designed to support my (*our*) entire family. The conference provides "camp" experiences for children with CHARGE and their siblings while their parents attend conference sessions. In addition, "Sibshops" are led by trained counselors who provide a safe and fun environment for siblings, 8 years and older, to meet their peers and share their life experiences and the emotions that stem from having a family member who has the multiple physical and developmental disabilities specific to CHARGE.

The CHARGE Syndrome conference always provides information on cutting edge medical, educational, genetic, and behavioral research and provides an opportunity to speak directly with the researchers as to ways to apply their research specifically to (*my/my child's needs*). It strengthens our family's bond with the worldwide CHARGE community of individuals and families who strive daily to deal with the challenges that CHARGE Syndrome brings. Spending a weekend with others with CHARGE (*or other parents of children and young adults with CHARGE*) is invaluable.

The cost for me/our entire family to attend the conference will place a significant financial burden on my family. The detailed costs of attending the CHARGE Syndrome Conference are detailed in Attachment 1. I(/we) have also applied to (*list other agencies you have contacted*) and have held(/plan to hold) the following fundraisers to help defer these costs (*describe the remaining gap between the costs and your resources*) but we will still need and appreciate any help you are able to provide.

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After the conference I will be happy to share information I gain from attending with your organization. I would be happy to speak to your group following the conference with a description of the program and to share information about multi-sensory impaired children/adults in general. I also hope to share the many things I learned at the conference with other parents in the community.

You can contact _____ at _____ to obtain additional information about me/my family and how beneficial attending this conference will be. *[Note: If you include this sentence, you should have already contacted a teacher, therapist, physician, etc. who has agreed to serve as your sponsor/advocate.]* You can also view additional information about CHARGE syndrome and the conference at the CHARGE Syndrome Foundation website (<http://www.chargesyndrome.org>).

My contact information is: _____.

Thank you very much for your consideration.

Sincerely,

Attachment 1

Detailed Costs to Attend the CHARGE Syndrome Conference

SAMPLE –Family of 4

Modify to reflect your actual expenses or use the Excel worksheet to create your own

Transportation

Airfare	\$400.00	x	4 <i>(number of people flying)</i>	=	\$1,600.00	
Shuttle/Taxi fare to/from Orlando airport					\$120.00	
Rental Car	\$100-\$200 per day					
Total Transportation Costs						\$1,720.00

Conference Registration*

Adult	325.00	x	2		\$650.00	
Child attending camp	325.00	x	1		\$325.00	
Child not attending camp <i>12 & younger</i>	225.00	x				
Person with CHARGE	no charge	x	1		\$0.00	
Conference Subtotal						\$975.00
Less 10% Discount for CHARGE Syndrome Foundation Lifetime Members						(97.50)
Total Conference Costs						\$877.50

Hotel

Rosen Shingle Creek	149.00 <i>per night</i>	x	3 <i>Thurs.-Sun.</i>	=	447.00	
Total Hotel Costs						\$447.00
GRAND TOTAL CONFERENCE 2017						\$3,044.50

*Registration fees include: "camp" activities for preteen children; conference sessions for adults and teens over 13; snacks and a light dinner on Thursday; breakfast, lunch, dinner and snacks on Friday and Saturday; and breakfast on Sunday