



Our RARE Bear program is supported currently by almost 2,000 RARE Bear makers who we fondly refer to as the RARE Bear Army. The Army spans 10 countries including 49 states in the US. We represent over 100 quilting guilds. RARE bears are made from remnant fabric making each bear one of a kind just like our one of a kind rare kids. Each RARE Bear has a serial number that ties the bear to the bear maker. Once a child receives a bear, we ask that a photo be returned to us so that we can forward the photo along to the bear maker. The RARE Bear Army motto is **"Helping Rare Kids One Bear at a Time"** and that is exactly what they do! These special RARE Bears not only bring awareness but also bring love and hope to rare kids and their families. It illustrates that together and united as a global community, we can change the lives of kids with rare disease! To participate in the program, please complete the [online request application](#). The request application has a section to enter the child's favorite colors and hobbies so that a perfect bear can be matched to the child. Once a month, our volunteers gather to find the perfect RARE Bear for our special RARE kids. RARE Bears are then packaged and mailed to our program participants.

## **RARE Bear Program FAQs**

**Is there a cost to participate in the RARE Bear Program?** No. There is no cost or fees required to participate in our program; although, donations to help offset the expense of shipping are very much appreciated. Please visit our website to obtain more information on how to donate <http://www.rarescience.org/donate/>

**How do I request a RARE Bear?** Please visit our website and complete the [online request application](#).

**Can rare disease groups, organizations and foundations participate?** Yes! For group RARE Bear giftings, please contact us at [info@rarescience.org](mailto:info@rarescience.org)

**Does your child have to be diagnosed with a rare disease to participate?** No. If your child is currently being tested or treated for an undiagnosed disease, they are eligible to participate as well.

**Are RARE Bears only for children with rare disease?** Although we understand the overwhelming need to support our adult rare disease community, the RARE Bear Program is designed for children who suffer from rare disease. Bears are available for individuals 19 years old and younger; or any age for a rare disease involving developmental and cognitive dysfunction.

**Why is there a serial number on the bear?** All RARE Bears have a serial numbered tag sewn into the back seam of each bear. These serial numbers tie the bear maker to the child. Each number is unique. This unique number also serves to help register the child into our database so that we can build patient communities with a goal of advancing research and to possibly help drive forward more immediate therapeutic solutions.

**How do I send a photo of my child with a RARE Bear?** Photos can be uploaded on our website using the following link <http://www.rarescience.org/child-photo-upload/> or you may email the photo to [info@rarescience.org](mailto:info@rarescience.org)

**Why do I need to send photo of my child?** Our one of a kind RARE Bears are hand made by quilters from all over the world. When we receive a photo of the child with the bear it is forwarded along to the amazing RARE Bear makers. It means so much to them to see the bears that they have so lovingly made in the arms of a child! We also like to share the photos on our picture gallery at: <http://www.rarescience.org/rare-bear-program/rare-bear-kids/> No identifying information, names or diseases are listed on our website.

**Do I have to send a photo of my child?** We understand your concerns for privacy. The photo does not have to have a picture of your child's face. You can share a picture of your child's hands holding the bear or a picture of just the bear itself.

**Where can I get more information on the RARE Bear Program or information on the RARE Bear Army?** Please visit our website <http://www.rarescience.org/rare-bear-program/> or contact us at [info@rarescience.org](mailto:info@rarescience.org)