



RARE Science RARE Bear Army Newsletter

Vol. 1 No. 3 December 2015

Happy
Holidays



Give the Gift of Hope to Rare Kids

In February 2015 RARE Science Inc., became a nonprofit 501(c) (3) organization to help patient families with kids with rare disease. We created our organization because collectively rare diseases affect millions of kids of which 35% die in the first year of life. There is an urgent unmet need to help these kids and **we need your help!**

Our mission at RARE Science is to accelerate finding therapeutic solutions for rare kids. A portion of what is needed comes from in-kind contributions of services, Sponsors, and also the extraordinary volunteers that help us with research operations and the RARE Bear Program.

"Rare Science acts as a catalyst, creating communication bridges between patients, researchers and clinicians. This new innovative approach to finding treatments and cures has accelerated a chance for our children with SYNGAP to live better lives."

**Monica Weldon; President/Co-Founder
Bridge the Gap - SYNGAP Education and Research
Foundation**

The number of children impacted by rare disease is staggering, and we aim to provide help and hope to these children in their lifetimes.

Of the 7000 identified rare diseases, 50% affect children. From this group, 30% of these children die before their 5th birthday. Rare diseases are responsible for 35% of deaths in the first year of life.

However, the rest must come through tax-deductible donations made by the RARE Science Community. While large donations are welcome and appreciated, donations of \$5, \$10, \$20, \$100 are welcomed with equal gratitude. As we have seen with the growth of the RARE Bear Army, the strength of giving is in the number of those supporting, not in the amount of the donation.

If you are able to help support us through a tax deductible donation please donate [here](#) or mail your donation to:

**RARE Science, Inc.
PO Box 231081
Encinitas, CA 92024**

A heartfelt thank you to all of you that have contributed to the groundswell of support this year - what we accomplished was beyond belief and I can only imagine the transformative changes we can bring to rare kids through RARE Science Research Programs in the New Year.

My warmest wishes this holiday season,

Chris



Fairfield World selects RARE Science RARE Bear Program for "Make for Good" spotlight!

Fairfield World highlights special organizations that are contributing to better communities through donation of time to people in need. "This good work spreads friendship, comfort, support and love in our communities and around the world."

RARE Science is honored to be a featured non-profit contributing to helping families' world - wide navigate and find therapeutic solutions for their children. By helping one family we help many, what we learn can be leveraged to other rare conditions. Only united can we change the lives of rare kids around the world and the RARE Bear Army is the united front that is changing lives of kids in real time. Thank you RARE Bear Army members for giving us this distinction that is recognized in our community!



Thank you Fairfield world for recognizing the RARE Bear Army and supporting us to change the live of rare kids!

Read more about 'We Make for Good' and the RARE Bear Program here:

<https://www.fairfieldworld.com/wemakeforgood/rare-bear-program/>

If you are a member of a guild, we would like to know. Please send your guild name to dleewalker13@gmail.com.

During the Dec. 5th holiday celebration, the quilters attending asked the RARE team if it would be possible for them to meet other RARE Bear members to build a RARE community. They are very interested in learning what techniques other quilters use, what drives them to make RARE Bears, and want a chance to share ideas. Follow us on Facebook for details on how we hope to connect our volunteers through a RARE Bear Army Community.



Support RARE Science this holiday season by shopping through our Amazon link: <https://smile.amazon.com/ch/47-1744221> and a portion of your holiday spending will go to RARE Science to accelerate cures for children with rare diseases.

*Amazon donates
when you shop at
smile.amazon.com.*

Find great gifts on the Holiday Toy List
and support us at the same time.

amazonsmile



Support Finding a cure for Kids with Rare Disease!



The RARE Bear Army is now over 300 members and we are finding that everyone may start with making one bear but once one is made, frequently we are asked for multiples of feet fabric. In the New Year, we not only see some bear making competitions arise but we have plans to launch some very fun RARE Bear making activities - stay tuned! This week I was brainstorming with Spoonflower on how to cover fabric costs and the estimate of fabric we would need for next year. I realized I would need at least 20 yards (720 RARE Bears) to get us potentially through March. About an hour after our call, I received a message from Spoonflower,

"I wanted to let you know that we would love to cover the cost of the 20 yards you plan on ordering today! Consider it your holiday gift for bringing so much cheer to the RARE Bear army and the children who are receiving the bears. You truly inspire our team to make the RARE bear army grow to its fullest potential!"



I am so thankful for our special relationship with Spoonflower, their support and commitment to grow our programs to help kids in the New Year. I am also grateful for each and every one that has volunteered and supported the RARE Science Mission. Yes, as individuals we can support our community but united we can make transformative changes in the lives of children!



RARE Science Salutes Its RARE Bear Army Volunteers with a Holiday Celebration

On Saturday, Dec. 5th the RARE Bear Team hosted a holiday thank you for its Southern California volunteers. Fifty-seven bears were exchanged for more tags and feet. Ideas were shared and a great time was had by everyone.

Attention San Diego County Quilters: our next workshop will be Saturday, Jan. 9th from 10 to 2-3 PM. The location is the clubhouse at the Sundance Mobile Home Park, 2250 N. Broadway, Escondido. We will have a few sewing machines for use and fabric. Come and join us to sew, cut fabric, embroider faces or stuff the bears. Drinks and coffee will be provided; feel free to bring a sandwich and your creative ideas!



Spotlight on RARE Bear Army Stars!



Have you been wondering who all these volunteers are that make up the RARE Bear Army? Each month we will introduce you to some of your fellow quilters. Kicking off this month are:

Celia - lives in Lake Worth, Florida with her son. Celia's husband was a heart transplant patient who lived longer than anticipated post-transplant, rendering each day they had together a gift. When asked why she sews RARE Bears, Celia answered she wants to give back. She knows what it's like to have a loved one with an illness and believes in living each day to its fullest and being thankful for the gifts each day brings her.

Haazra - resides in Fredericksburg, Texas with her husband. We had quite the surprise when we opened her box of bears. Not only were the bears beautifully hand crafted, but they each had a matching cape! The detail Haazra added to the eyes and mouth is stunning and makes the faces come alive!

Corinne - our dear friend from The Netherlands! Corinne's bears have had the longest journey so far. The bears landed in southern California last Saturday and it was quite the arrival at our local Post Office. Even the US Postal Worker got in a picture! The bears, like all your bears, are unique and beautifully crafted, including a little home-town fashion from their cold climate - each bear is wearing a scarf! Corinne also designed each pattern piece similar to a quilt - each one is made from fabric sewn together!

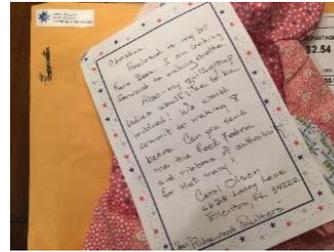
Carol - sewing her bears in Ellenton, Florida, Carol included a sweet note that her group, The Ridgewood Quilters, wanted to make eight bears!



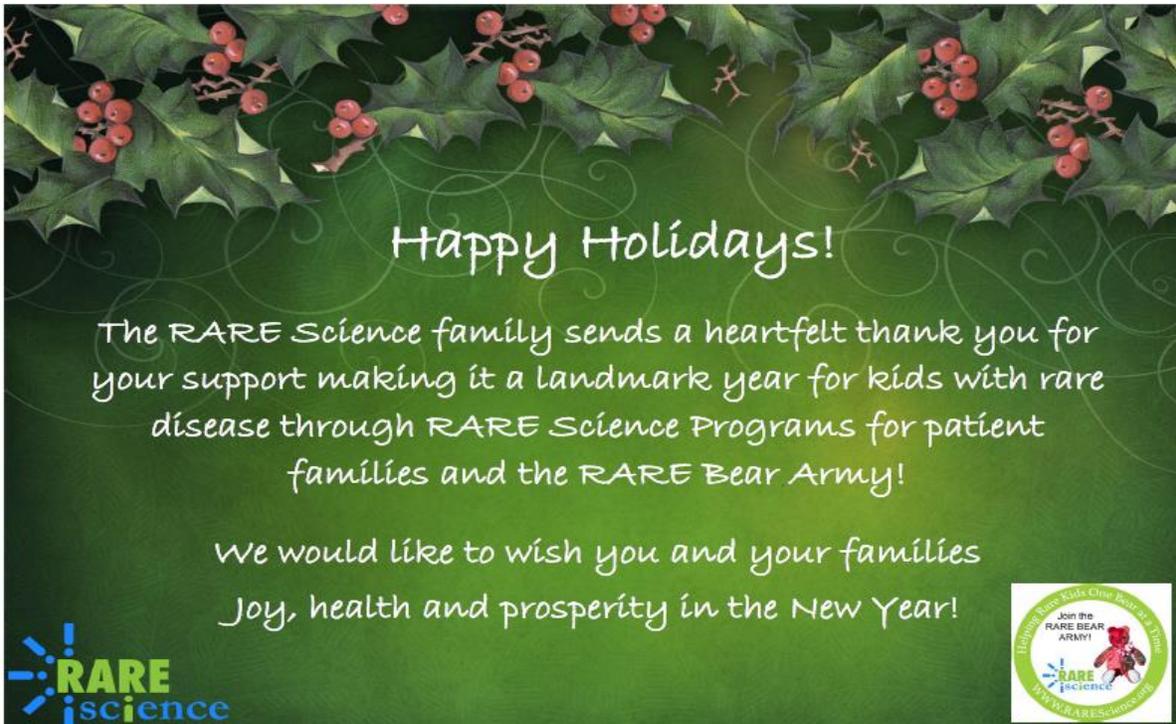
HAAZRA



CORINNE



CAROL

Happy Holidays!

The RARE Science family sends a heartfelt thank you for your support making it a landmark year for kids with rare disease through RARE Science Programs for patient families and the RARE Bear Army!

We would like to wish you and your families Joy, health and prosperity in the New Year!