

RARE Bear Army is one year old!
See page page 10.



RARE Science

RARE Bear Army Newsletter

Vol. 2 No. 4 October 2016

Thank you Rare Bear Army for all that you do! Rare Science could not do this without you!

Your Rare Bears were recently gifted to a special group of C.R.M.O. kids – here is what they have to say:

"Thank you, RARE Science and the RARE Bear Army, for the bright light that is shining out from our CRMO Facebook group this week. So many photos of kids who have just received their RARE Bears! I just read a post from a mom's whose child just had a rough doctor's appointment, meds aren't working, scans were scary, but her daughter was excited to go to the appointment—so she could show here RARE Bear off to her care team! The timing of the bear distribution is good. In the last 6 months, two families on the list got the devastating news that their children, initially diagnosed with CRMO, were actually facing cancer. Both families have stayed in touch with the list to give updates on their kids, and we're grateful to be able to continue offering moral support to the parents. But news like this, and candid posts that share failed treatments, little ones in pain and threadbare parents, reflect just how hard rare disease is on everyone. A little bit of relief and joy and inspiration goes a long way. RARE Bears showed up this month and provided a bright spot, a bunch of smiles and a chance for everyone to associate good feelings with the word RARE for a while."



"Olivia is getting ready to teach her first grade class about C.R.M.O. Since she's been having a tough time this year, we figured it might be a good time to help educate the class in kid friendly terms. Thankfully Olivia has her rare bear to help teach what it means to be rare! I have to admit I'm a little nervous to hear how it goes, but I know she's a brave girl!"



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Fund My Way Home Campaign

Rare has embarked on a "Fund My Way Home" effort to raise money for shipping your one-of-a-kind Rare Bears to their new home. We have been very fortunate to have all of you join our Rare Bear Army in making much-needed Rare Bears, that we are creating a fund to support shipping costs to their new home.

Please know that we are not asking the Rare Bear Army members for donations. We are so grateful for everything you already do to help our Rare Kids in donating your time, energy, creativity and fabric stash to make bears. Can you help us in spreading awareness of our funding campaign?

As word of the Rare Bear Army and community of Bears we have built spreads, more and more families are joining the Rare Science network in the hopes of getting better and faster treatment for their child. The result is greater demand for your Rare Bears. If you know of family and friends that want to help ship these bears to their new homes, please share this with them. A link to the Go Fund Me campaign to help us cover the costs of shipping the bears is below.

Our needs are simple. A donation of \$7 is enough to send a Rare Bear to his or her new home in the U.S. A donation of \$20 sends a Rare Bear to one child internationally.

By sending a RARE Bear home to a child, each donor becomes part of this world-wide effort to connect patient communities in accelerating cures for kids with rare disease, and changing the lives of Rare children. Please help us spread the word.

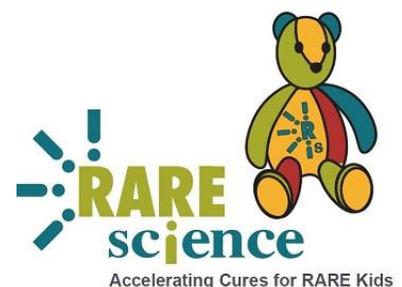
<https://www.gofundme.com/sendararebear?ssid=742668607&pos=3>

Check out our Facebook page. See the smiling faces of the kids with their own unique Rare Bear. If you're not a Rare Bear Army member, join us!

This is why we do what we do.
<https://www.facebook.com/RAREScience>

Join the Rare Bear Army!

- Support life-changing research,
- Make a special friend,
- Bring a Smile to a Rare Child.





Rare Bear spotted in England!

Isabella's Mom sends her thanks to the Rare Bear Army:

"I wanted to say a huge heartfelt thank you for my daughter's Rare bear. It arrived today to Essex, England & as you can see from my pictures Isabella loves her already! We have named her Faith as a reminder to never give up!"

It is absolutely lovely & perfectly fits the guide I gave to her favourite things. Your team are truly amazing for doing such a lovely thing for our special children."

*Many thanks
Carly*



Shhhhh....we have a secret! Some Beary exciting news to share with all of you. And when you hear what it is, you are going to want to join the fun! Stay tuned....



Rare Kids from San Diego's undiagnosed group show off their Rare Bears!



Rare Science & Rare Bear Army is in the news:

Our innovative research strategy is driving cures for ADCY5 patients through the California Regenerative Medicine Institute Stem Cell program and modeling how we can accelerate finding cures for all Kids with rare disease.

<https://blog.cirm.ca.gov/2016/09/12/making-a-deposit-in-the-bank-using-stem-cells-from-children-with-rare-diseases-to-find-new-treatments/>



We were very interested in the fairies Christine Fuqua of Richmond, Tx., puts on her Rare Bears. Here is what she told us: *"I love making items a little more special for kids. I have never had to go through a serious illness with a child but cannot fathom what that would be like. I have an embroidery machine and thought I would make these bears a little more special. I use embroidery patterns on them and thought what a good idea it would be to make rare bears very special and one of a kind just like these brave kids."*

Marcia Schulman & Friends - Smithtown NY



Annette Celestian - Baldwinsville NY



Jane Collins - Jacksonville FL



Lisa Connery - New South Wales, Australia
These bearskins had the longest journey to reach us and came with a note of love!



Vivien Garrigues, Rowena Hayes and Andrea Blodgett - Spring TX



Christine Fuqua - Richmond TX
Love the fairies! (see note from Christine on page 3)



Patricia Weissensee & Friends - Sacramento CA



Leslie Lee - Sulphur LA
Rare Bears and cards of love for the kids!



Anitra Kerr and Eagle Scouts in Salt Lake City make more than 70 bear skins in support of kids with rare disease! Ranging in age from 12 to 17, they love being involved in this project and from delivering flyers to 200 homes to collecting donations and finally getting together to cut out the fabric, they got a sense of the labor of love involved in cheering up these kids. A couple of these boys have siblings with special needs so it made it extra special for them.



We received 51 bearskins from the ladies at the Willamette Valley Chapter of ASG with a

This has been a lovely project to work on and we appreciate the opportunity to do something worthwhile for the very ill children your program supports.

Sincerely,

Sally
Sally Braswell, asgbraswell@q.com
Willamette Valley Chapter
American Sewing Guild



HUGE thank you to Marge Passalacqua and the Quilters by the Sea from Florida! Look at these gorgeous bears! Minnie Mouse, butterflies, Puppy dogs, Florida Gators, monkees – outstanding!



Lisa Story - Ramona CA

From Mickey Mouse to Hello Kitty to Camouflage to Minions!
Juanice Hess - Sacramento CA



BIG shout out to the Girl Scouts of San Diego County who stuff all those bearskins our Army sends in. Thank you girls!



Leslie Lee - Sulphur LA
Rare Bears and cards of love for the kids!



Bearskins from the Lone Star State!

Debbie Alexander and her ladies from the Common Threads Quilt Guild in Gainesville and Lake Kiowa Quilt Guild sent gorgeous bearskins and asked for more feet fabric and tags! Go Texas!

Bernina Bears!



Can't you just hear this Bear when he meets his Rare child for the first time? *"Here's looking at you, Kid!"*



A special shout out and thank you to Jill Kubitz and friends from Bernina Sewing/Design, Las Cruces NM: Jean Long, Lynn MayLone, Lucy Mitchell, Susan Brown, Sandy Tutor, Mary Jane Smead

Check out the embroidered faces on these bears!

The last couple of weeks have brought us many new Rare Bear Army members from the Bernina community. We are very excited to have them join our group and can't wait to see what they create!

The Rare Bear-Child Matching Process

Some of you have asked us what happens to the Rare Bears once you send them in to the Rare team. This process accounts for time for bear placement and receiving a picture.

The Rare Bear MASH Unit looks at every bear to ensure there is nothing that could put its assigned child at risk. The bears are checked to make sure they are made of 100% cotton, there are no pieces attached that could be removed by a child, such as button eyes, that all seams are properly closed to prevent the stuffing from coming out, and the bear's authentication or donor tag is inserted in the back seam.

The Rare team then identifies the best child to receive the bear based on age and gender. They review information provided by the parents such as their child's favorite color, hobbies, if they have a favorite movie character (Minions, Batman, Frozen...). A great deal of effort is put into the matching process, and judging by the gallery of photographs on our website (<http://www.rarescience.org/rare-bear-program/rare-bear-kids/>) the kids love their bear from the minute the box is opened. As many of you know, we request a photo of the child with their Rare Bear, which we in turn send back to the bear maker. There sometimes can be a delay in getting the photo from the family, but rest assured, when we receive the photo, it is sent to the bear maker to enjoy as quickly as we can. Not all families will provide a photo, and in those instances, we endeavor to let the bear maker know the Rare Bear they so lovingly created has a new home.

RARE Science and the RARE Bear Army are going to the International Quilt Festival Houston!

Nov. 2 - 6 | George R. Brown Convention Center | 1001 Avenida de las Americas | Houston

Are you going? Let us know - we want to meet you! Rare Science will have a booth at the show with amazing give aways! Please stop by and see us. We are also having a A Beary Rare Affair on Friday night. You can see all the details, view the Celebrity Bear collection and register for the event on our website here: <http://www.rarescience.org/beary-rare-affair-event/>. the celebrity bears are being revealed one at a time and the ones currently revealed can be seen at <http://www.rarescience.org/category/celebrity-bears/>

At the Beary RARE Affair, we'll be stuffing bears, meet your fellow RBA members and mingle with Celebrity Bear Makers. On display will also be our one of a kind collector Celebrity RARE Bears that will be part of a silent auction held during the Festival. **Have an opportunity to win a Bernina!** Other give aways include celebrity autographed books and patterns, gift baskets and other exciting surprises. Come help us help kids one Bear at a time, mingle with friends and celebrities.

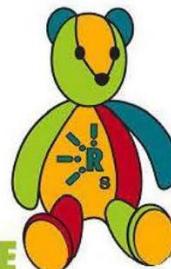


Help Kids with RARE Disease and Win a Bernina at the International Quilt Festival Houston



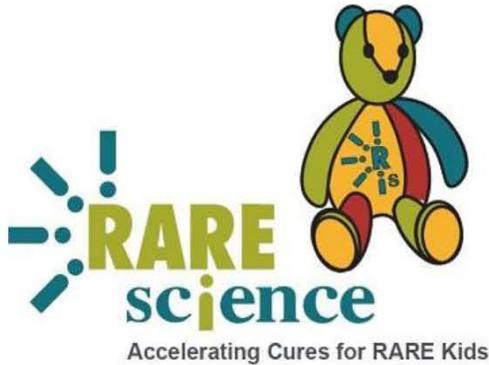
November 4, 2016
6 - 8pm
Convention Center - Ballroom A, 3rd Floor
\$25 entry, two tickets for Bernina and other gift drawings and give aways

A Beary RARE Affair
2016 International Quilt Fest
Houston, Texas



Stuff a RARE Bear for RARE Kids, Meet Celebrity Quilters and get a chance to Win a **Simply Red Bernina** and many other gifts!





Bid and Win a collector's item RARE Bear made by your favorite Celebrity Quilter. Each One of a Kind Bear represents the style and skill of each One of a Kind Celebrity Bear Maker!

Celebrity RARE Bear Silent Auction November 2nd, 5pm through 6th, 12pm

A special one of a kind opportunity to bid and win Celebrity RARE Bears made by the hands of Celebrity quilters! These one of a kind collector bears were made from 24 celebrities that put heart and soul into making a one of kind RARE Bear representing their style and personality. All proceeds will go toward RARE Science RARE Bear Program and Research Programs that accelerate finding therapeutic solutions for the 200 Million kids that are undiagnosed or have a rare disease.



Our RARE Bear Program is made up of 700 RARE Bear Makers around the world (we span 9 countries and 45 states in the US) that we call the RARE Bear Army. These dedicated volunteers sew each bear, and mail them to us unstuffed. At our headquarters, we have more volunteers that fill the bears with soft stuffing, and then sew the seams shut, along with packing and shipping the bears to children around the world! For each of the amazing RARE Bear makers, we send a picture of the child with their gifted bear that they made back to the maker. **We hope you considering joining the RARE Bear Army!**

How To Join the Silent Auction and Win a Celebrity RARE Bear

To See the Celebrity Bears

- All Celebrity Bears will be located in the RARE Science Booth at the International Quilt Festival November 2 – 6 in Houston, Texas
- However, you do not have to be present to bid or see the bears as we are using an easy to use online auction site

To See and Bid on a Celebrity RARE Bears

- Access the Celebrity Bear auction using the following link <https://www.charityauctionstoday.com/auctions/rare-science-celebrity-bear-auction-944> or, go to <https://www.charityauctionstoday.com> - select Charity Auctions at the top of the page and

enter RARE Science in the search box through a computer or smart phone. If you need help come by the RARE Science booth at the festival and we can help you register to bid.

- Once you locate the auction, you will be asked to register for the auction by creating a bidder account using a credit card. Your credit card is safely stored in an encrypted environment. Your credit card will only be charged if you win auction items. You are now ready to start bidding!
- The Charity Auctions Today platform sends two types of out-bid notifications. We send out bid notices by Email and by SMS Text Message. You will find the opt-in/out option on the Bidder Profile page.
 - Email – This is sent by default to the email address used when registering.
 - Text – To receive a text message out bid notification please opt-in to receive text messages when you register. If you did not opt-in during registration, you can out-in/out at anytime from inside your bidder account.
- When you win an auction item, we will notify you by email for each item you won. Shortly after the winning notification email, you will receive a second email that will contain a link to view your invoice. When you click the link within the email, it will bring you to your bidder account. From there you can view the invoice and the item you have won!

For Assistance in getting more information and help bidding email us at rarecelebbear@gmail.com or call [\(619\) 414-1234](tel:6194141234) or visit our booth



There are approximately 200 Million kids worldwide that have rare disease – 35% of these kids do not celebrate their 5th birthday. Help us change the lives of children with rare disease.

RARE Science accelerates finding therapies for kids with rare disease by empowering patient families/foundations with tools that help with community awareness and patient outreach through our RARE Bear Program. We also drive research by pooling knowledge and providing research tools for specific diseases so we can understand the biology that is responsible for the observable traits of rare disease. This helps identify therapies that may help in the more immediate. We unite patient families, clinicians and researchers across the globe to accelerate finding cures for the most vulnerable patients, our children! For more information, please see our website www.rarescience.org

RARE Science, Inc., a 501(c)(3) nonprofit organization, is qualified under Section 170 of the Internal Revenue Service Code to receive gifts, grants, & contributions which are deductible for federal income tax purposes



Happy 1st Anniversary RARE Bear Army!

It is so hard to believe it has already been one year since the RARE Bear Army was formed! We have grown tremendously over the last twelve months and are so grateful that all of you have joined our ranks to help kids with rare disease.

The pictures in this newsletter say it all. The kids love the bears you create but your RARE Bears also have brought such increased awareness to the medical needs of these kids. You have heard the staggering statistics: two hundred million kids worldwide have rare disease - more than one-third won't celebrate their fifth birthday. We have to work together to make a difference for these children.

With your help, we will do it. Your Army has grown to well over 1,000 members, representing 9 countries and 47 U.S. states. Let's make it all 50 states. We need Delaware, Hawaii, and Washington DC. If you know any quilters in those three states, let's get 'em!

We have 3,000 bears in process and want to double our efforts in 2017. Help us help Kids with rare disease. Many of you have asked if we could use help operationally. If you would like to explore opportunities to be more involved, stop by the Rare Science booth at the Quilt Show or send an inquiry to dwalker.rarescience@gmail.com.

Thank you all for your wonderful contributions. You are the foundation of the Rare Bear program and we could not do this without each and every one of you!

And our utmost thanks to our sponsors for their outstanding support of our programs.

The Rare Science Team

BERNINA
made to create

Simplicity

 Spoonflower

The Quilt Show  .com

 Quilt Alliance
Document • Preserve • Share

 Fairfield
A Quilted World

sulky
Express Yourself 

 Mountain Mist