

RARE Science RARE Bear Army Newsletter

Vol. 3 No. 1 January 2017

Happy New Year to the RARE Bear Army!

RARE Science goes to Quilt Show in Houston!

RARE Science and the RARE Bear Army had a fabulous time at the November Quilt Show in Houston. We made many new friends, and enjoyed meeting bear makers and sponsors that we have worked with over the past year and a half.

Thank you to our sponsors for their support of our work and generosity in donating items for our Friday night Beary RARE Affair event.



A very successful bear stuffing party! Over 200 bears were completed.
Thank you RARE Bear Army!



We have a winner! Christina Waters and Heather Lofstrum of Bernina present the Grand Prize of a Bernina Red machine and "Bearnina" to Christine Herron

In this issue....

Houston Quilt Show	1
2016 RARE Science Year in Review	1
A Beary RARE Affair	2-4
RARE Bear Mania	5
RARE Partners with Retrophin	6
Friends Forever	7
2017 Calendar of Events	8
RARE Science News	8
RARE Bear Matching Process	9

2016 RARE Science Year in Review

What a year it has been! We've seen growth in our RARE Science programs, collaborations with other organizations, and a tremendous increase in the RARE Bear Army. Enjoy watching a recap (click here):

<https://www.youtube.com/watch?v=otHKAF6nFOk&t=7s>

The Grand Prize giveaway - the Bearnina bear created by Rosie de Leon-McCrady and the Bernina Red sewing machine, generously donated by Bernina.



Setting the tables for a fun night of preparing RARE Bears for gifting.



Even a signature cocktail!



The Celebrity Bears line up under the watchful eyes of our volunteers from the University of Houston

And a BEARY BIG shout out to Linda Pumphrey of Mountain Mist for shipping in a pallet of 200 pounds of Fiberfill for the stuff-in party!



We are very thankful to Lilo Bowman from The Quilt Show and Mary Kay for coordinating the Celebrity Bear Auction and introducing RARE Science to so many new friends and supporters. We are so grateful for your friendship and support - we could not have done this without you!



WE ARE PROUD TO HAVE YOU AS OUR SPONSORS!

BERNINA
made to create

Simplicity

sulky
Express Yourself

 **Spoonflower**

The Quilt Show.com

 **Quilt Alliance**
Document • Preserve • Share





Fairfield
FIBERFILL

THANK YOU SPONSORS AND CELEBRITY BEAR MAKERS!

Drawing prizes were generously donated by Sponsors and Celebrity RARE Bearmakers for the Beary RARE Affair and give-aways in the RARE Science booth.

Alex Anderson - Autographed book, Quilt Show ruler and mat cutter

Allie Aller - two autographed books

Sue Nickels - three copies *Feathers and Fillers*, three sets of patterns: Ashley's Flower Basket, Jessica's Flower Basket, Circle Round the Stars and three sets of Sue Nickels King Tut Tone on Tone threads

Jamie Fingal - 2 hand-drawn coloring books

Simplicity - design books, an automatic bobbin threader and a great Everything for stitching kit

Ricky Tims - five yards of gorgeous hand-dyed fabric

BERNINA - Simply Red 215 machine

Sulky Threads - Sulky gift basket Slimline box of their 12 wt. Cotton Petites and a package of Sulky Stick n Stitch. Sulky also donated spools for the Beary RARE Affair guest gift bags and 50 spools of thread for sewing the bears at the stuff-in party.

Rosie de Leon-McCrary/Scarlet Today - creator of the beautiful "Bearnina", also donated 12 wt. and 16 wt. Perle Cotton by Presencia floss for embroidery on bears and size 7 embroidery needle packets

Mountain Mist - generously donated stuffing for the 200 bears for the Beary RARE Affair party.

The RARE Science Team was very excited to meet RARE Bear Army members from the following Quilting Guilds. Having only exchanged emails and phone calls for a year, it was great fun to finally put faces with the names!

Guild members from the following groups joined in the fun at the RARE Bear Stuff In party:

Amador Valley Quilting Guild - California
Austin Area Quilt Guild - Texas
Back Road Quilters - Maine
Calhoun County Quilt Guild - Texas
Dallas Quilting Guild - Texas
Farmington Valley Quilters - Connecticut
Gold Triangle Quilting Guild - Texas
Kenai Peninsula Quilting Guild - Alaska
Quakers Quilters - New York
Quilt Guild of Greater Houston - Texas
Seward Area Quilters - Alaska
Smithtown Adult Education - New York
Tall Pines - Texas
Tri-County Quilting Guild - Texas
Willow Spring Quilting Guild - New Mexico

We are very grateful to the following Celebrity Rare Bear Makers who donated their time and creativity to make unique one-of-a-kind Rare Bears for the online auction. See the attached PowerPoint slides to learn more about the Celebrities and their fabulous bears!

Alex Anderson
Allie Aller
Becky Goldsmith
Gyleen Fitzgerald
Jamie Fingal
Lea McComas
Karen Bernstein
Lola Jenkins
Lyric Kinard
Melody Crust
Nancy Brown

Rosie de Leon-McCrary
Sue Bleiweiss
Sue Nickels
Tamara Leberer
Victoria Findlay Wolfe
Youngmin Lee
Leslie Tucker Jenison
Katie Fowler
Ricky Tims
Rob Appell
Wendy Grande



Join the RARE Bear Army!

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



Old and new RARE Bear Army members are lucky winners of a variety of drawing prizes generously donated by our sponsors and Celebrity RARE Bearmakers.



Christina Waters, CEO/Founder of RARE Science, RBA member Marcia Schulman from Smithtown, NY and Debbie Walker, Director, RBA Operations (L-R) finally meet after working together for a year.



Over 200 bears stuffed and a good time had by all.

RARE Bear Mania!



Susan Dey and the Sedville Crazy Quilters making bears in Missouri



Pamela Newsome's gorgeous bear all the way from Scotland!



A bundle of bearskins from Karen Despot in Virginia



Barbara Johnson of southern California sent a pair of bears



Another gorgeous RARE Bear from Pat Gardener in Florida



Lisa Connery's RARE Bears from New South Wales!



Busy in Texas - Diane Adams - Suhar sent beautifully made bearskins



Kathy McKinney and members of the Quaker Quilt Guild in New York made 22 bears and there are more to come!

RARE Science and Retrophin Partner to Stuff RARE Bears for NBIA Patients



Retrophin is a biotech company that plays an active role in the rare disease community. The company contributes to the betterment of patients by developing treatments for rare diseases, such as [Pantothenate kinase-associated neurodegeneration \(PKAN\)](#), one of many NBIA disorders, as well as by partnering with patient advocacy organizations in support of the rare disease patient community. Furthering the company's support their RARE Bear Program, Retrophin partnered with RARE Science on an initiative to stuff RARE Bears that will be gifted directly to the NBIA patients attending the [NBIA Disorders Association's Ninth International Family Conference](#) this summer, June 1-4 in Deerfield, IL. <http://www.nbiadisorders.org/family-support/nbia-family-conference/2017-conference>



Mark your calendar for March 18th – the next *Spring Into Action for Kids Sew-In!*

Once again, Spoonflower is working with RARE Science and the RARE Bear Army on another international sew-in day. RARE Bear Army members and guilds from around the world will gather with friends and spend the day making RARE Bears.

Whether you are with a group or individually in the comfort of your home, we would LOVE for you to join us. More details to come – stay tuned!

"Our family conference will be that much more special with the personal touch of RARE Science and Retrophin. We are thankful for the support of our families and the joy that will be brought to our children by a gift of a RARE Bear made just for them."

-Patricia Wood, Founder and President of the NBIA Disorders Association.

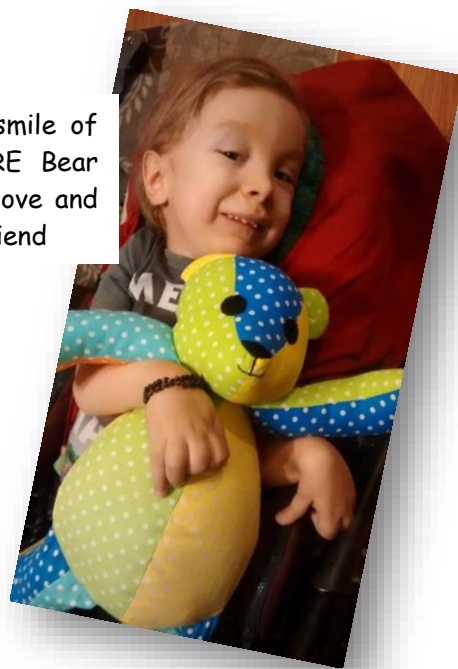


Friends Forever...



Savy received her RARE Bear "Petal" on her birthday!

Wade gives a big smile of thanks to his RARE Bear maker for putting love and care into his new friend



Jarret's new friend arrived just in time to help with a difficult day of medical appointments.



Getting acquainted – precious moments.



Benji & Bear!

Danielle's Mom tells us she LOVES her new RARE Bear.



Check out our Facebook page. See more 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>

2017 RARE Science and RARE Bear Army Calendar

Below are some of the events and activities planned for RARE Science and RARE Bear Army in the coming months.

February- RARE Bear gifting to SMA, Bohring Opitz, Alagille Syndrome Alliance

February - Potential Thermo Fisher Innovation Nation - one hundred 5th graders will participate in a RARE Bear stuff in

March - International Sew in with Spoonflower, Spring into Action for Kids

June - RARE Bear Man Sewing Program video taping with Rob Appeal

September 11- NCL stuff/sew in 200 ladies

September 28-30 - San Diego Quilt Show

November - Houston Quilt Festival, ALD awareness month

RARE Science in the News

Meeting the scientists who are turning their daughter's cells into a research tool - one that could change her life forever...the Grossman Family journey.

<https://blog.cirm.ca.gov/2016/11/01/meeting-the-scientists-who-are-turning-their-daughters-cells-into-a-research-tool-one-that-could-change-her-life-forever/>

Patient Advocate Leads Drive to Add Rare Diseases to CIRM's Stem Cell Bank

<http://www.rarescience.org/2016/11/03/patient-advocate-leads-drive-to-add-rare-diseases-to-cirms-stem-cell-bank/>



Lizzie and Mr. Bear - lovingly made by Cindy Kok of Cache, OK

RARE Bear #1191 completes his journey to England!

We received the sweetest note from Lizzie and her Mom, letting us know Mr. Bear arrived safely at their home in Devon and is already hard at work putting a smile on Lizzie's face.

"Just wanted to say a huge thank you from Lizzie in Devon England. She is totally thrilled with her RARE bear named "Mr Bear". He has been on many adventures already. He likes shopping and holidaying in our touring caravan. She can't believe the great adventure he's had just getting to England. I cannot thank you enough for making her so happy. What you do for these children is absolutely amazing. Her bear's number is 1191. We would like to say a special thank you to the person that has made this bear. Also your selection process is brilliant."

This is why we do what we do!

The RARE Bear-Child Matching Process

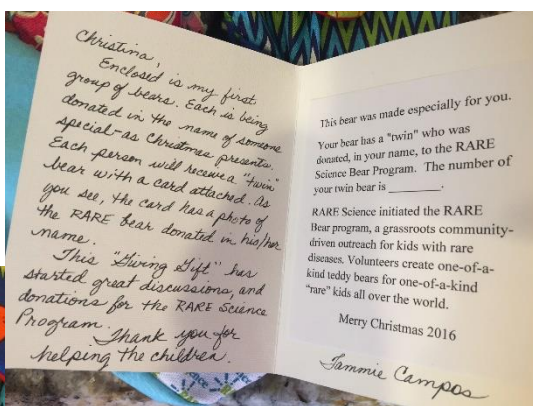
Some of you have asked us what happens to the RARE Bears once you send them in to the RARE team. This process accounts for time for bear placement and receiving a picture.

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.



Why we do what we do: sweet Nova received her bear at a gifting just last month. Back in the hospital, her RARE Bear Sparkle is right by her side!

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.



For every bear Tammy Campos and her quilt group made, they also made a "twin" bear which was given as a Christmas gift to someone special along with a sweet card explaining the "twin" RARE Bear being gifted to a child with a rare disease.

