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Accelerating cures for kids

Helping Rare Kids One Bear at a Time
Join the RARE BEAR ARMY!
WWW.RAREScience.org

RARE Science
RARE Bear Army Newsletter

Vol. 2 No. 1 January 2016

Calling all quilters to *Spring into Action for Kids*!

Spoonflower, as many of you know, is a great supporter of RARE Science. They print the RARE logo fabric for our RARE Bear feet, and is coordinating a fabulous event in which we hope you will participate. Spoonflower is holding a "sew in" on Saturday, March 19th in their Green House in North Carolina. They are inviting their local members to join forces and sew as many RARE Bears as possible in one day, expecting 25 to 30 participants who will share the tasks of cutting, sewing, stuffing and embroidering.

We would like to expand this to all locations and challenge all RARE Bear Army members to gather their troops and participate on the 19th, creating a little friendly competition among the quilting guild community by holding your own independent event. Recognizing not everyone belongs to a guild, we welcome all individual sewers as well.

(continued – see page 2 "Spring into Action")

North County Quilters' Assoc. of Escondido supports RARE Science

At their Jan. 21, 2016 meeting, the North County Quilters' Association in southern California presented Christina Waters, CEO/Founder of RARE Science, with a gift of $1,000 to help fund RARE's research activities.

"I am so moved by the generous charitable donation by the North County Quilters, founders of the RARE Bear Army," said Christina Waters "which will help us further grow our Research Programs to accelerate therapies for kids with rare disease." ***(continued – see page 3 "NCQA)***

Dr. Waters, Founder/CEO of Rare Science, thanks the NCGA for their generosity and support, as Guild President Carrie Harrison displays the bear pattern and a RARE Bear

RARE Bears for Kids and Donors that support our RARE Research Program

Many of you ask what the difference is between serial number tags and donor tags, and the purpose the tags serve. They both serve very important roles that help us help rare kids in a profound way. The serial number tags are identifiers for tracking the bears that are received by the kids that enroll in our program. The kids love the bears and we often get stories that once they get them, they never put them down. The bears also have a wonderful effect on patient families and are a way to unite families all over the world that have children with rare disease. This is important for supporting the patient family community but not the end to the needs of patient families.

(continued – see page 2 "RARE Research Program)

Rare Disease Day®: Feb. 29th, 2016

Rare Disease Day® takes place on the last day of February each year. The main objective of Rare Disease Day is to raise awareness among the general public and decision-makers about rare diseases and their impact on patients' lives. Learn more about the history of Rare Disease Day.

The 2016 global theme, "Patient Voice," recognizes the crucial role that patients play in voicing their needs and in instigating change that improves their lives and the lives of their families and carers.

The National Organization for Rare Disorders (NORD) is the official Sponsor of Rare Disease Day in the United States alongside our sister organization, EURORDIS (The European Organization for Rare Disorders), which organizes the official international campaign. Over 80 countries participated in Rare Disease Day 2015. To learn what's happening around the world, visit the global Rare Disease Day website at rarediseaseday.org. ***(continued – see page 2 "Rare Disease Day)***

Spring into Action (continued from page 1)

Whether your Guild participates as a group, or you are sewing from the comforts of your home, we want to hear your ideas for March 19th. For example, **The North County Quilters' Association of Escondido** will utilize their monthly workshop on March 19th to *Spring Into Action* making RARE Bears from 10 a.m. to 4 p.m. Lunch will be provided, all fabric will be pre-cut and ready to get started.

Kathi Martin of Arizona, who just became a RBA recruit in early January, will *Spring Into Action hosting* her quilting group, Jack's Jills, at her quilt shop, The Jack of Arts, from 9:00 to 5:00 on the 19th. For those who don't sew but want to contribute, Kathi will have kits of fabric available for a donation. The funds will go to RARE and Kathy and her team will complete the bears. Kathy and crew will also sew bears every Wed. night in March!

Whether you sew, embroider, or prefer to cut fabric, we would love to have you participate. If you have friends or family who don't sew but can help with a charitable donation, it will support our research programs and operations of our RARE Bear Army. Anyone able to help support us through a tax deductible donation may donate here.

In order to prepare the feet fabric and authentication tag packets and ensure we get supplies out to everyone, it's important you let us know if you will participate either individually or with your Guild.

To get your Guild prepared for March 19th, please provide us with the expected number of participants for your independent event, we will mail you all the necessary supplies. That applies to all individual participants as well. The most important information we need from you is how many people you think will participate as part of the Guild, or if you want to join as an individual from your home. Please send this information to dleewalker13@gmail.com no later than February 19 to allow us to prepare the supplies for mailing.

PLEASE send us pictures or video of your event so we can share them with all RBA members via the newsletter, our website and Facebook page. This will be a very exciting day and how better to spend a Saturday than sewing RARE Bears with good friends and family! Please send your bears back to us flat!

All of us at RARE Science are extremely proud to be part of the Army and have the opportunity to work with all of you. We can't say thank you enough for all your efforts, energy and creative ideas! Together we can make a difference for rare disease in children.

What: ***Spring into Action for Kids***
When: March 19th
Where: Your favorite sewing spot
Why: Create RARE Bears for RARE kids
RSVP by Feb. 19th!

Rare Disease Day (continued from page 1)

Anyone can get involved in Rare Disease Day awareness. On this site, U.S. participants can find, suggest and get involved in events taking place across the country. **Join the conversation on Facebook, Twitter and Instagram! Use the hashtag #RareDiseaseDay to help us make the day trend worldwide again this year!**

RARE Research Program (continued from page 1)

Donor tag bears play a vital role when we gift them to those who financially support the programs we offer patient families. Funds raised from donations go toward not only supporting families but critical activities that help accelerate identifying real time therapeutic solutions for our rare kids. To do this we need to compare the similarities and dissimilarity of as many children with the disease to find out what is causing the illness. To this end activities include: 1) retrieval of medical records of rare kids for the patient families- this can include several hospitals and thousands of pages. Some of our families are in different countries as well. 2) Programming a new tool for patient families to self report seizures, behaviors and activities that bring on illness; 3)building a neutral computational platform for patient families, clinicians and research to share and advance finding ways to help.

Our team includes, to offer these resources to families, computer programmers and architects, data entry and medical record specialists, project managers, geneticists, researchers and many more. Although many of our team are volunteers there are operational costs to support these efforts. In addition, in the coming year we want to scale to support more families and would like to hire experts to manage and grow certain aspects of our programs. The Donor Bears play, now and in the future, a large role in bringing awareness to our efforts to help rare kids and help us cover crucial operational costs for our programs.

Thank you so much for supporting making both types of bears! We also thank you for spreading the word to those that don't sew but want to make a charitable donation to the RARE Science mission. Together we can transform the lives of these special children!!

★ ★ ★ *Spotlight on RARE Bear Army Stars!* ★ ★ ★

Introducing…Kathi Martin, Owner, The Jack of Arts

Kathi just joined the RARE Bear Army barely a week ago and is already busy making plans to help RARE. Below is a compilation of messages we received from her which we wanted to share with you.

I truly have been blessed. I don't have anyone in my immediate family or among my friends that suffer from anything more serious than diabetes (both sisters). My Dad passed away in May from complications relating to COPD. I'm healthy; my husband's healthy, as well as our daughter and her family. I contribute regularly to St. Jude's Children's hospital as a thank you to the powers that be that we have not been touched with serious illnesses in our family.

I originally came across the Rare Bear Army on The Quilt Show, an online show hosted by Alex Anderson and Ricky Tims. I believe it was just a quick article about your organization with a link to purchase the pattern from Simplicity. Those patchwork bears really spoke to me and so I did a little more research and decided I know enough like-minded quilters that we can have fun doing this for the kids and your organization. My little shop has become a gathering place for quilters and there are some amazing women I know will be happy to be a part of this. I love having people in my store sewing. We don't have a local guild any longer, so I love that some are gathering at The Jack of Arts for their quilting fix. Anyway - this will be fun for all of us!

NCQA (continued from page 1)

Carrie Harrison, Pres. of the Guild explains what this donation means to the members, "The North County Quilters were the founding Guild of the Rare Bear Army and are quite proud of this fact. We are so happy to be able to use our sewing skills to brighten the life of a 'Rare' child. It has been such a blessing. There are so many special children and for them to receive a bear from a stranger, someone maybe thousands of miles away, that cares. How incredible is that? This year, we granted financial support, to this very worthwhile endeavor as it moves globally in the hopes of reaching more children."

Join the Rare Bear Army!

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

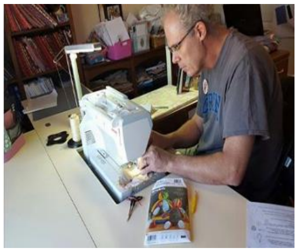
It's not only the RARE kids who benefit from the RARE Bear Army but the Army volunteers as well!

Ann Bixler recently contacted us expressing an interest in joining our ranks of volunteers. As we traded emails with Ann, it soon became apparent that our Bears do as much for the quilters creating them as they do for the Rare kids who receive them.

Ann and her husband David, both Virginia natives, met at McDonald's (of all places) in Virginia Beach when Ann was home for summer break from college. Married 26 years, they relocated to Arizona 10 years ago, where David, a structural engineer, owns his own business.

Ann's love for quilting started after she took a class at Joann's. She then joined AZ Blankets for Kids and attended the quilting bees to learn more. That led to her involvement in Quilts 4 Kids, and her quilting group made wheelchair robes for veterans who live at the Veterans long-term care facility.

(continued – see page 4 "Ann & David Bixler)



David, on one of his good days, making a rare bear, knowing how it feels to have your life sabotaged by a rare disease and wanting to help. He designed, cut and sewed the bear with very little help from Ann.

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The Quilt Show.com

Q U I L T S I N C

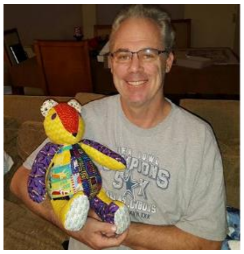
Ann & David Bixler (continued from page 3)

Five years ago, their lives were hijacked when David was diagnosed with a rare brain disease. Ann posted these pictures of David sitting at the sewing machine making bears, and here is what she told us. *"We hate feeling so powerless. He is so excited to have found this outlet to do something to help others. David believes that by letting kids and families know that they are not alone, he can help take some of his power back."*

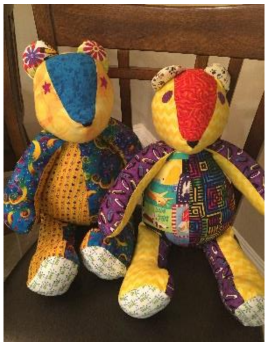
"Last March we traveled from our home in Arizona to Cleveland Clinic, and the first thing the doctor said was 'I can't help you. There is no treatment for this.' Even an experienced English teacher myself could find no way to properly communicate what it feels like to hear that while simultaneously living in a world where we can watch movies on the telephone."

"Just last week David and I had a difficult conversation about how hard it is to find purpose in your life when many of your days are spent in illness instead of wellness. Being able to make bears has enlivened him from what had become a bit of a depressive state. The project is something that he can do at home at his own pace and on days when he has the energy and is relatively pain free."

"So, please know that it is our family who thanks you for the opportunity to turn heartache into hope."



Dave and Boscoe the Bear from Arizona



David's gorgeous bears arrive in San Diego ready for gifting!

Welcome, Ann & David, to the RARE Bear Army! We are so grateful you joined us and that our RARE Bear project brings hope and joy to you both.

Welcome to our RARE Bear Army new recruits!

Becky Creighton, Urbana OH/Champaign Quilters Guild
Maureen Bird, Holliston MA/County Line Quilters
Kathi Martin, Safford AZ/"Jack's Jills"
Nancy Domenico, Sarasota FL/American Sewing Guild and Smocking Arts Guild of America
Dorothy H. Dey, Dousman WI
Janice Quick-Wolfe, Yucapai CA
Shelda Schimmel, Tulsa OK
Annette Israel, Lindenhurst IL
Jessica Lee, Amity OR
Claire Gottschalk, Beaverton OR
Dawn Orr, Ashburn VA
Anne Toschi, Burlingame CA
Preyna Shah, Sugar Land TX
Paula Martin, Llano TX
Carol Bonfiglio, Aurora CO
Carrie Muetzel, Logan OH
Ruith Lewis, Benson AZ
Lisa Harris, Elk Grove CA

Going to QuiltCon -- Pasadena CA -- Feb. 18 – 21? Let us know!

If any RBA members are planning to attend next month's QuiltCon in Pasadena CA, please let us know. Emma Parker of the Quilt Alliance, has graciously offered to represent us and we are asking RARE Bear Army members attending QuiltCon to bring their bear skins (unstuffed bears) to The Quilt Alliance booth. Emma would love to videotape a short interview with our members attending on what the RBA means to you, what motivates you to make RARE Bears, and have you in any way been touched by a rare disease. If you are going to QuiltCon, we would love to introduce you to Emma and arrange for a personal interview. Please email Debbie Walker atdleewalker13@gmail.com if you are planning to attend and she will help with the next steps.

Enter The Quilt Show's RARE Bear Game Day Sew-In Contest!

While the gang is gathered around the TV watching the big game next Sunday, Feb. 7th, stitch up a "bear skin" for a child with a rare disease AND *be entered to win an iPad Mini 2!*

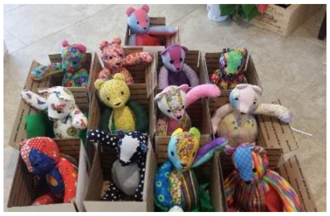
Here are the rules:

1. ***You must be logged in first to enter your photo. All members are included: Free and Premium "Star".***
2. ***If you are not a Free Member, just click on "Join Free" in the brown menu bar at the top of the page.***
3. ***Once you are in the RARE Bear Community area, click on the blue "Join Group" button to join the group.***
4. ***Click on the photo icon to upload your photo.***
5. ***Don't forget to write - RARE Bear Contest Entry and your name in the Status Box.***

Visit The Quilt Show at https://thequiltshow.com/ for more details.

So, if you post your "bear skin" image by Sunday, March 20, you will be entered into two contests: one for the iPad Mini and one for the International Quilting Weekend contest. (Yes, Rare Bear makers are allowed *TWO* entries into the International Quilting Weekend Contest). So that's two ways to win and help out a child. Didn't make it by February 8th? Make sure you still upload your photo and you will automatically be entered to have a 2nd chance to win in the International Quilting Weekend Contest. During International Quilting Weekend, Rare Bear makers will be allowed to enter a 2nd time in the regular contest!

Then gather all of your supplies and start sewing your 'bear skin.' Once the 'bear skin' is completed, upload the photo of your handiwork on our RARE Bear Community area by Midnight on Monday February 8, 2016 to be entered in the contest.

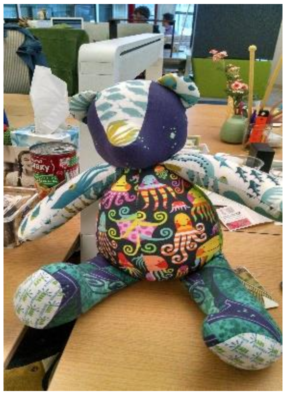


RARE Bears wave goodbye as they embark upon their journey to meet their assigned RARE child!

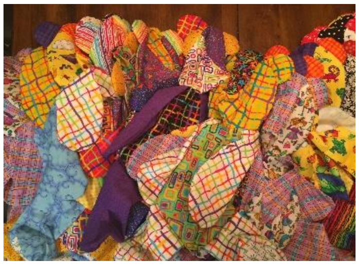
This group of bears were gifted to RARE kids in our ADCY5, SYNGAP and undiagnosed programs.

Safe travels!

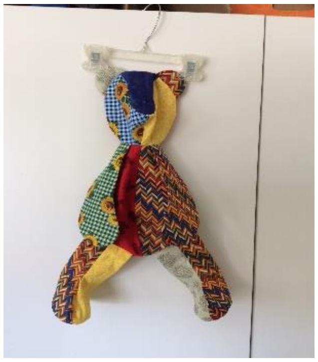
See the RARE Bears who recently arrived at the RARE Science office in Southern California:



SPOONFLOWER'S UNDER THE SEA BEAR



A PILE OF BEARSKINS FROM MJ OLINGER!



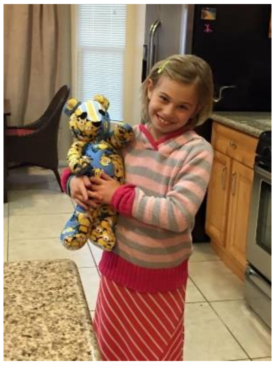
LINDA PETERSON

We want to hear from you!
Visit us on Facebook https://www.facebook.com/RAREScience/

- Post a picture of your bear or your Guild in action.
- Share a story of how rare disease has affected you.
- Post a review of the RARE Bear Army and what it means to you to make RARE Bears.
- Send us a video of your bear-making efforts

Post a review online with Simplicity http://www.simplicity.com/rare-bear-sewing-pattern/UC5461OS.html
Were you able to order the pattern online? What do you think of the instructions? Need more detail on any of the steps?

We were recently contacted by a RARE patient's Mom who shared with us her daughter Payton's request for a "Minion" RARE Bear, thinking chances were pretty small one would exist. Lo and behold, the RARE team acknowledged receiving one from Pat Hobbs, a RARE Bear Army member in Macomb IL. *Minion Bear* was quickly sent off to Payton and one look at her smiling face reinforces why we do what we do. Thank you, Pat, for your awesome creativity and support of the RARE Bear Army project!



PAYTON welcomes her RARE Minion Bear

RARE Science in the News!

- RARE Science story and mission in Dec. 4, 2015 Union Tribune, San Diego. Read it here: http://www.sandiegouniontribune.com/news/2015/dec/04/one-on-one-christina-waters/
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- RARE Science shares the critical need for participant family support and its boomingly successful RARE Bear Program. Listen here: http://www.rarescience.org/2015/12/07/ut-san-diego-interview/
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- Christina Waters, PHD, MBA, CEO/Founder is plenary speaker at CSU Program for Education and Research in Biotechnology (CSUPERB) and RARE Science a sponsor of the CSU 28th Annual Biotechnology Symposium, in Anaheim CA January 7-10, 2016. Read more: https://www.facebook.com/RAREScience/photos/pb.294936630662286.-2207520000.1453649316./441578735998074/?type=3&theater

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