

Support Finding a cure for Kids with Rare Disease!



## RARE Science RARE Bear Army Newsletter

Vol. 2 No. 2 February 2016



### *Spring into Action for Kids!*

The March 19<sup>th</sup> Spring into Action for Kids National Sew-In is right around the corner! Guilds and individuals are participating from all over the world in this fun and exciting event co-sponsored by Spoonflower and RARE Science.

Thank you all for your support. Don't forget to send us pictures of your day sewing Rare Bears. We would love to have videos too! **Post your pictures on our Facebook page** and tell us how many Rare Bears you made!

Thank you Spoonflower for making this happen! To learn more about the National Sew-In, click here: <http://www.rarescience.org/rare-bear-program/rare-bear-sew/>

### ***A very special request from the Rare Bear recipient families -***

They want to get to know their child's bear maker. We are beginning to receive requests from the parents of Rare children asking for information on the volunteer who made the Rare Bear their child received. The bears have such an impact on not only the child, but on the family as well. Click here to see Hannah as she meets her Rare Bear for the first time: <https://youtu.be/rF7NqvtvGXl>.

If the Rare team receives a request when your bear has been gifted, we will let you know and ask your permission to release either your email address or your mailing address so the family can communicate their thanks to you directly. If you would like to include a note to the family when sending your bears to us, we would be happy to pass it along with the bear.

We are also sending the bear makers a photo of their Rare Bear with the recipient child. We recently received this message from Roberta, whose bears are gorgeous:

*"My heart deepened when I received a letter with a photo of the most precious little girl holding the bear I made. It made my offering more personal.*

*After teaching pre-school for 40 years and retiring five years ago, I now sew and knit and pick up my grandson after school each day. My husband passed away four years ago from Lymphoma, so my family knows first hand what trying times are experienced. Other than creating something for someone to hold in a time of comfort and perhaps a bit of joy, I cannot think of anything else I would like to do for others. Words cannot express how valuable and vital Rare Bears is to us, the maker and to the receiver."*

The Rare team often receives words of thanks from Rare Bear Army members expressing how much being part of this project means to them. We, at RARE Science, want to say thank you to all of you for being part of this journey with us. We could not do it without you and together, we can make a difference.

## Rare Bear Gifting at Sanford Burnham Prebys Medical Discovery Institute



**READY FOR ASSIGNMENT!**  
RARE Bears preparing to meet their RARE child



### A message from RARE Science Founder/CEO Christina Waters

"I am so grateful for everyone's time and commitment to the vision to deliver a better way that can accelerate finding more immediate therapeutic solutions for rare kids. It is truly amazing how fast and far we have come in the time we started! A heartfelt thank you! We gifted over 20 bears to rare children attending the Sanford Burnham research symposium on Saturday, Feb. 27. The bears are truly magical bringing joy to the kids and uniting the patient families. The support is so appreciated that some of the families have asked to know about the bear maker and if it would be ok to reach out to them to thank them."



### **RARE Science in the News!**

Southern California is becoming the hub for rare disease research – read here how RARE Science and the Rare Bear Army play an important role in making that happen.

<http://www.illumina.com/company/news-center/feature-articles/southern-california-becoming-hub-for-rare-disease-research.html?linkId=21738002>



## The Rare Bear Army thanks The Quilt Show for their Game Day Sew-In Contest!

Final numbers are not yet available but the Rare Science team is receiving a lot of bearskins. Our San Diego volunteers comprised of Alpha Phi Omega, Girl Scouts and other community members are busy stuffing and preparing the bears for gifting. We are so grateful to The Quilt Show team for their outstanding support.

Leslie Lee's bears came with little hearts embroidered with "You are loved"



Kathi Martin



Emma Thompson



Joyce Pfeiffer



# SPRING INTO ACTION for kids with Rare disease! March 19, 2016

Donate now at  
[www.rarescience.org](http://www.rarescience.org)

Your charitable donation will support materials and shipping of RARE Bears to Rare Children around the world and the RARE Science Research Programs that empower patient families find therapies that can help their children.

**Donate now and Help us Help RARE Kids around the world!**



**Girl Scout Troop #4491** volunteered recently to stuff Rare Bears. Comprised of 15 Juniors (most of which are in 5<sup>th</sup> grade and are 10-11 years old), Troop #4491 meets at San Pasqual Union School near the San Diego Zoo Safari Park. Here they proudly show off their afternoon's work of getting the Rare Bears ready to embark upon their journey to meet their Rare child.



LINDA PETERSON

**Bear Mania!**  
Here is a sampling of Rare Bears that have arrived in San Diego. After a little stuffing and prep work, they are ready to go to work and meet their Rare Child.



JANE HANNAH



ANN SANTISTEVEN



SHEILA STERN



KATHY KENNEDY DAVIS



SUE DUISENBERG



DIANA MACFARLAND



DIANE CLARK



MILLIE SHENTON



PATTY GARIANO



IDA COPELAND



## Carrie Muetzel, Logan Ohio

Carrie joined the RARE Bear Army in January and has become a dedicated bear maker. We've come to know Carrie through her whimsical emails, where we read of her interesting life's journey. From Hammi, her 800 pound pet pig, to how she cooked dinner outside over a live fire every night, Carrie has had an adventurous life.

During a blizzard, Carrie hosted the family at her house, cooking meals in the fireplace and enjoying the fact there were no cell phones or TV to interrupt quality family time. Losing power won't stop her from making bears. She has a foot pedal sewing machine and like the Energizer bunny, will keep going and going on her Rare Bears!



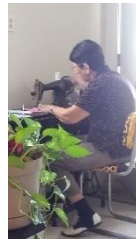
Carrie's grandchildren after a day of Rare Bear making!



**Spotlight on RARE Bear Army Stars!**



Ofelia's armful of Rare Bears



## Ofelia Fuentes and Pat Cadena

Ofelia sews Rare Bears on her Mom's sewing machine. Born and raised in Comstock, Texas, she sewed for the public without any schooling. She says "Thank God I never ruined anyone's garments". Pat Cadena, her daughter, told us "Many times her sewing helped put food on our table and after my dad's passing, she put me through school. An amazing woman and my role model."

**Our thanks to you both for joining the RARE Bear Army!**

## 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
- Start a dialogue with other guilds - share information - find out all about your fellow Rare Bear Army members

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?

**Simplicity**

 Spoonflower

 **Quilt Alliance**  
Document • Preserve • Share

*At the heart  
of your project*

The  **Quilt Show**.com

 **Quilts Inc**

**Fairfield**

## Rare Bear Construction Questions

Our Rare Bear Army has grown to more than 500 quilters and we have gotten many questions and suggestions! We thought to share answers and ideas that would maintain RARE Bear style but also allow for some creative license!

**Eyes and Nose:** The eyes and nose should be embroidered. There is a reference in the embroidery instructions to using buttons to mark the correct spot the eyes should be located. The buttons are only used for eye placement and sizing and should not be sewn onto the bear due to potential risk to the child if removed. If you are not able to embroider, we can complete when we receive the bearskin from you.

**Tags:** The tag should be sewn into the center back seam about 1.5" from where the head joins the body (and sewn-in a little past the end of the tag). If the tag extends into the area marked to be left open for stuffing, you can either adjust the opening down farther, or stitch the entire center back seam and leave an opening for stuffing on the side seam.

**Ears:** Even though we suggest you return bears unstuffed, the ears are stuffed slightly when attaching to the head.

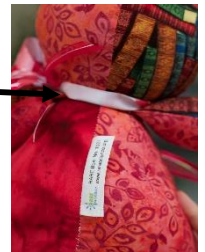
**Fabric:** the Rare kids have a multitude of medical complications. Our medical advisors have requested the bears be made from only 100% cotton unused fabric. Fabrics such as fleece, flannel, or minky shed lint which can affect the child adversely. We want the bears to be a quality the child can hug and sleep with, since many of the kids don't let them go once they see how unique and truly rare they are.

**Size:** The Rare Bears are 18" in size. We are aware the Simplicity pattern envelope indicates View A, B and C, which are the 22" size bears and will try to have this corrected.

We take extra care to match your bear to the child's age, gender, personality and medical conditions. We have been able to identify kids to receive bears that were beautifully made but outside the above guidelines, but it will be easier to match your bear if the above guidelines are followed. If you have any questions on how to embellish with your own creative ideas, please do not hesitate to contact us. We have received some quilted bears, eyes with beautiful embroidered eyes, capes, hearts to insert when stuffed, and with their own blanket. We love seeing everyone's own style come out!



Head joins  
the body  
here



Members of Alpha Phi Omega joined the RARE Bear Army last month. Here they display the bears they stuffed and prepared for gifting to Rare kids.

### Join the Rare Bear Army!

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

Sabina and Friend

