

 Outlook

Thanksgiving 2024

From BCM Families Foundation <info@bcmfamilies.org>

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To info@bcmfamilies.org <info@bcmfamilies.org>



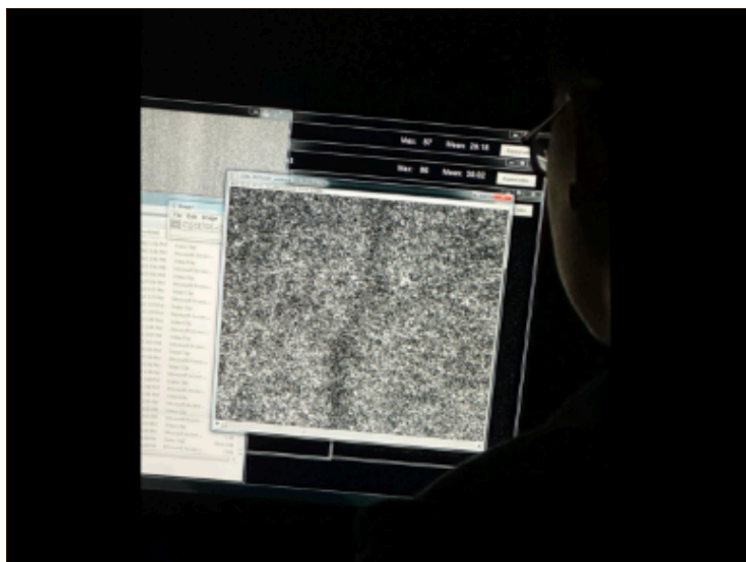
Dear Families, at this time of Thanksgiving celebration, I would like to extend my gratitude to every member of this wonderful community.

The 2024 special thanks is for:

1) First of all, to all adults and, above all, children who have joined the BCM Patient Registry at <https://www.BCMRegistry.org> or have participated in clinical studies at the University of Pennsylvania or have organized educational events. Thank you! You have done an important difference. Particularly I thank Rachel's son for this beautiful work:



And Kristy's son for his participation in the University of Pennsylvania clinical studies:



A big thank you to our Registry Manager, Sara Cammarota and to all scientists working at the University of Pennsylvania who produced very important results published here:

<https://www.mdpi.com/1422-0067/25/19/10639> giving to our community endpoints for a clinical trial and a clinical trial protocol.

Today I thank all people in our community:

2) **Directors:** Kay McCrary, Barbara Wade Sergent, Marylee Dilling, Ned Reade for their commitment and work. A special thank goes to Marylee Dilling who at the end of September represented in an engaging and superb manner our community at the Ocular Diseases Forum, in front of many important people, including clinicians, experts and FDA and EMA representatives.

3) **Ambassadors:** Angela M. Tucker, Mark Young, Nicole Kim, Trudi Dawson, Caspar Wohlfahrt, and Julius Bolay .

4) **Volunteers:** Dean Monthei for his continuous support to all members of our community on visual aids, for his beautiful pieces for the BCMFF Newsletter, and for Demo Glasses project. Mary Dilling for thanking donors. Lindsey & Ray Egner for fundraising and awareness activities. Manuele Freda, Trudi Dawson, Emanuele de Bon, Francesca Noto for the BCMFF Newsletters and beautiful art graphics.

5) **Monthly Donors, Big Donors and all donors:**

Thank you to all donors because without you we couldn't make any project:

Cesira Alquati, John & Leah Cavitt, Kristy Countryman, David &

Mary Dilling, Lindsey Egner, Mike Fry, Toby Harris, Robert and Joan Hicks, Janice Ishee, Nan Johnson, Kay & John McCrary, Michael McMahon, Kathy Molohon, Dean Monthei, Sean Monckton, Denise and Chris Pratico, Elizabeth Prince, Ned Reade, Sue Rowland, Renata Sarno, Robert Severs, Richard Schickler, Marine Slatter Chapuis, Robert & Donna Taylor, Mark & Diane Young, and all those who donated, participated in fundraising events online.

6) **Participants:**

Thanks to Bradley Harrison and Mike Fry for their participation in “60 sec with...” interviews . <https://www.blueconemonochromacy.org/60-seconds-with/>

7) **Scientists:**

We thank all scientists of the BCMFF Scientific Advisory Board for their continuous support:

Dr. Jeremy Nathans, Dr. Artur V. Cideciyan, Dr. William W. Hauswirth, Dr. Bernd Wissinger, Dr. Jacque Duncan, Dr. Alessandro Iannaccone, Dr. John G. Flannery.

Doctors who participated in the BCM Patient Registry:

Dr. Tomas Aleman, Dr. David Birch, Dr. Marc Mathias, Dr. Pierre Bitoun, Dr. Cristina Irigoyen Laborra, Dr. Katarina Štingl, Dr. Mark Pennesi, Dr. Alessandro Iannaccone, Dr. Joseph Carroll, Dr. Amy K. Hutchinson, Dr. Jacque Duncan, Dr. Lucia Ziccardi, Dr. Elisabetta Martina.

Doctors working on BCM projects:

Dr. Tomas Aleman, Dr. Artur Cideciyan, Dr. WenTao Deng, Dr. Susanne Kohl, Dr. Bernd Wissinger, Dr. Matthieu Quinodoz, Dr. Carlo Rivolta, Dr. Jay Neitz, Dr. Joseph Carroll.

We thank many other scientistis and doctors who offered their advice or review of materials, including: Dr. Laura K. Windsor, Dr. Luis Dell’Osso, Dr. Jay Neitz, Dr. Susanne Kohl and all others around the world who have been working on BCM.

8) **John Cavitt**, Blue Gen Therapeutics Foundation and Adverum:

I would like to thank John Cavitt today in particular, for all he is doing to fund the gene therapy clinical trial. John is putting his skills and work to raise funds for the trial and we are all so grateful to him.

9) **Friends and sponsors:**

A special thanks to Elisabetta Luchetta and the Associazione Acromati Italiani onlus <https://www.acromatopsia.it/> for their

support with 5xMille fundraising events, and to Konecta SpA <https://www.konecta-group.com/it> for supporting our projects in 2024.

I wish to all of you a happy Thanksgiving and I am so grateful today to have met all of you who are part of this very close and active community.

Renata Sarno, Ph.D.
President
BCM Families Foundation



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