# Cure JM Advocates Present **Proclamation of Thanks to NCATS**



The Cure JM Advocates Council, patients, and families proudly present a Proclamation of Thanks to Dr. Joni Rutter and her team at the National Center for Translational Sciences at the NIH for their work in critical research, drug discovery, and clinical trial breakthroughs in juvenile myositis.

## **Patients**



# Kendal T. Thank you so much for all of your hard work! I would've never had a chance at a "normal" life if it hadn't been for your dedication. I truly thank you from the bottom of my heart!

Kristen C. Thank you for supporting Cure JM in helping find a CURE! Tina M. You are the reason our children will be healed! Thank you for your work! You are saving lives!

Allison K.

Sienna T.

Maya R. Cure JM and the JM experts have helped me so much! Maya V. Please help figure out the cure or treatment that reduces the amount of medication I had to take!

Marlowe D.

Maddie S.

Kymm H. Fight for a cure.

Kristen W. Thank you for all that you do! As a patient with JDM for the past 20 years, I look forward to breakthrough in new anti-inflammatory medicines that won't have the side effects of steroids or the risk of immunosuppressants. I encourage more study in the area of gut health- the body's microbiome and it's relation to autoimmune diseases. Thank you again for your persistent efforts

Kendal T. Thank you so much for all of your hard work! I would've never had a chance at a "normal" life if it hadn't been for your dedication. I truly thank you from the bottom of my heart! Gianna G. Everyday gets better . Keep your head up James B. Isabella L.

Gretchen M. .

Darcy S. Thank you for researching this rare disease, when so little is known about it and it is incurable and very hard to treat. Although it isn't common, I thank you for continuing to research into this for me, as a patient Thank you Colleen K. Thank you so so much for all your hard work!! Courtney C. Thank you Catie Beth C. Maya L. Please help find a cure for us Juvenile Myositis warriors. Annalise T. Thanks for all the work in research and development for patients that have JDM Anna R. SO GRATEFUL!!! Andrew B. Thank you!! I'm 7! Adrienne N. Thank you for your dedication and continued research to understand this rare disease. It means so much to those currently battling JDM and those whom have fought and won. Signed, a JDM survivor in remission for 30 years. Aiyana J. Don't give up Abby P.

Ashley G.

## Parents

Zina C Sandi H. Yan M. Never give up! Xamayta P. Never give up hope! Jeff R. Embrace each moment as you are in it. wiebke w. It does get better! I was devastated when my daughter was Diagnosed. Now she competes in Wrestling, swim meets, Fast pitch and Skis every Saturday. Yes, she is still on meds. Sue C. CureJM!!!! Wesley M. A positive attitude is a little thing that makes a big difference. Victoria M. Every day we fight! Let's keep going! Amy G. Thank you for all the work you do for rare disease! #curejm Victoria R. Alicia V. Cathy V. Waiting for a cure Thank you for all you do Tyler S. STAND & FIGHT! Kids with JDM need more help. Tommy S. Thank you! Tamara S. Jill Z. Thank you for all the support! Christing M. CureJM Rebecca T. We truly appreciate all you do. My son is doing amazing despite the meds he is on. We are thankful they are working! Tiffany P. Tiffany C. Thank you for conducting critical research on Myositis! We have hope for a cure thanks to you! Tiffany C. Thank you for everything you do to advance research for rare diseases like Juvenile Myositis! Tiffany H. Tiffany H. Words cannot express our gratitude towards the NCATS for the hard work and dedication they do to help families going through these trials and tribulations have HOPE for better treatments and one day a cure! Victoria T. Victoria T. Thanks for all your hard work! We are forever grateful for what you do & the sacrifices you make. CureJM wouldn't be where it is without your support. Thanks a million Marlowe F. Kristine S. Tayler-Ann B. Mary Lyn S. Keep the faith! Everything is gonna be okay again in God's perfect time Amy B. Thanks for all that you do!! Kim G. Thank you! Suzanne F. Suzanne E. Thank you for all you are doing to support research and better treatments for juvenile myositis.



#### Jane M.

Stephanie S. Thank you for all you do! Your work is changing lives! Nicole A. Nicole A. Stephanie T. Your work gives me HOPE for my child's future! Thank you! subhasree s. Hang in tight... patience is the key Sharon O. Sue I. I admire these kids that have the strength encourage and facing this rare disease head on true inspirations to us all. Susan W. Thank you for supporting our children and families! We appreciate the hard work you put in find treatments for our kids! Shawn S. Jennifer A. Your work has contributed so much to patients and caregivers. I don't know where my daughter's health would be if it weren't for the new treatments that have come from the NIH's research, innovation and sound science. Thank you so much! Shannon C. Sarah S. Simonetta D. Sincere thanks for making a difference for our children living with JM. Sarah H. Samantha C. Thanks for your support! Sarah F. Sarah F. Stephanie T. Scott T. Our family appreciates every bit of support provided to Cal as he battles JDM! While great strides have been made, a cure is needed to truly let impacted children have a full and healthy childhood. Shannon T. Susannah M. Your work DOES MATTER! Thank you for helping us get one step closer to a CURE! Ryan D. Kerry B. Rhonda M. Talented doctors and passionate families through the support of Cure JM Foundation are making great strides toward a cure/remission! Yvonne D. Thanks for your work! Rebecca V. Rachel R. Never give up Rachel N. Thank you! Linda A. Thank you for all that you do!! Rebecca K. Thank you for caring about our rare and awesome kids! Rebecca K. Polyana N. Patricia L. Patrice M.



## Mira M. Thank you - what you achieve affects kids all over the world, including mine here in Australia

Nicole C. Marcus K Nora-Lee R. We need to find a cure!!!! Mandrake H. Thank you for all you do, researching to help my Nimat S. We are grateful for your hardwork and hope that you kiddo's life better. We appreciate everyone who helps our battle would come up with a cure soon. against JDM. Nimat S Nikki L. This work is so critical for my child. Thank you so SO much. Stefanie C. Nikki H. Thank you! Lynair B. Niele S. Natalie R. Nicole M. Luke R. CureJM Warriors Rock!!! Nick P. Thank you for everything you do for our kids! Nereyda B. Together we are strong! Natalie R. Natalie K. continued research! Natalie K. Lucille Z. Nancy S. Thanks for all you are doing to find a cure for JDM Laura T. Nancy M. Nancy O. Thank you for continuing to search for a cure for our kids! Linda T. Please find a cure Nancy O. Mark N. Linda T. Hoping for a cure! Molly T. Please help This cause! Crystal S. future ! Mandy W. Mandy W. Mira M. THANK YOU FOR CARING! everything to our family! Mary H. Mira M. Thank you - what you achieve affects kids all over the world, including mine here in Australia Lisa R. Twin JDM mom here! Mira M. Thank you so much! Your work is helping people with rare Lisa R. diseases all over the world, giving hope that there will be a cure grateful for the advances in treating this rare diseases. one day. Michelle B. Michele R. Rae-Chen C. hope the wellness back to you soon. Micheke R. Lineke K. Michael H. Please find a cure! Thank you Lila S. Melissa P. Melissa P. for these mighty warriors! Melissa G. Laura R. Megan R. The research of rare diseases is so important to families like ours. Our daughter, Rooney, has Juvenile Dermatomyositis. We have hope for a CURE because of the dedication and work that paths and challenging the norm! is put into researching better medications, treatment plans, and

eventually a cure. Thank you!

Megan M. Thank you for your help to better my rare child's tomorrow.

Megan M.

Sarah M.

Mary S. Cure JM and NCATS do valuable work for my daughters rare disease.

Mark N. JDM impacts my daughter's life every day even though we're considered "in remission".

Maryalice H. Life saving work-thank you is an understatement Lucy O. I'm proud of my daughter and her courage and bravery Shelby L. We hope for continued support and knowledge, studies that open the door for additional treatment options. Thank you for Laura T. Thank you for the wonderful work you do to support those who are fighting JDM. May you be blessed for your dedication. Lorraine G. Better treatment and hopes that a cure is in the near Lorin B. Thank you so much for helping these warriors battle all that they should not have to as a growing young person. Your work is Doug T. Words cannot describe how thankful we are for the tireless work done to make JM patients have a better quality of life! Elizabeth S. Thank you for your continued research. Our family is Elizabeth R. We need to find better treatments and a cure for JM Elizabeth B. Please continue to seek out disease specific treatment Leah K. Thank you for diving deep into the research to help find a cure for my child! Keep asking questions, going down different Leah K. Thank you for investing your time in finding the best treatments for my little girl. You make a difference in the lives of children with JDM. THANK YOU! Laura P. Help find a cure for our daughter!! Teresa L. Our daughter was diagnosed at age 3. We are so very

thankful for everyone who continuously work to help our loved ones. Thank you, thank you!! Please keep at it knowing that you are deeply appreciated!!!

Shari S.



Kahla G. Thank you so much for all your hard work !! Jessica D. Kristine A. Jerrica H. Kristine S. Thank you for all your work to find a cure for this rare Jennifier H. jennifef I. i am inspired by every person living with JDM, for they are disease@, Kristen H. the most profound teachers, and strongest warriors. Karen B. Thank you for continuing research. It's important and Jeff B. makes a difference to so many, including my family. Jeanie H. From the bottom of our hearts, we thank you!! Kevin C. Maddy, we are so proud of how far you come. Especial-Jean P. Is important to contribute to the cause ly, being an ambassador for other children with JM. Love you so Richelle V. Thank you so much let's continue to support for the a better normal living of our JDM warriors! Kelley C. jamie s. Cassandra C. James T. Thank you for helping our Lucy find confident footing to Kerry A. Thank you for continuing to pursue new treatment options walk out her JDM journey. for our JDM kids! Jada E. Thank you and Thank you!!!!! Javod G. To all the researchers dedicated to finding answers Indu S. More work needs to be done Iris H. and treatments for juvenile Myositis, your work is invaluable and offers hope to countless individuals and families. Your determi-Jessica C. Stay strong! nation and passion drive progress and inspire us all. Thank you Helen M. Giving Hope, Thank you for your relentless pursuit of knowledge and solutions for this Helen T. Stay strong rare disease. Hayley P. Thanks for the support! Kate S. Elizabeth L. Katie S. Thank you for all your hard work and research in helping my Courtney K. Thank you for supporting our rare kiddos!!! We couldn't daughter live the life she deserves. push forward without you!!! Kate B. Thankyou for your care and efforts to better care for our Jennifer G. Thank you so much for your life changing work! Geethanjali R. One day at time and keep looking forward Fred K. Go Katie Ethan Z. Thank you for all you've done! Jessica P. Erin H. My daughter's life is soccer. Without you all, my daughter would have not been able to play again. Thank you from the Julie H. Thank you to everyone involved in researching juvenile mybottom of our hearts! ositis! It means the world to my daughter to have a higher quality Erik H. of life and fewer side effects. Let's keep up the incredible progress! Karen E. Julie H. Thank you for all of your work involving JDM! We are so Emily H. grateful that strides are being made to give kids with JM their Erin C. Thank you for incredibly valuable work! childhoods back as quickly as possible. Thank you!! Elizabeth W. Jason P. Keep fighting! ELENAMARISOL T. We are on your side! Josh C. It's hard, it takes time, but things get better. Elizabeth G. Elena K. Debra R. Johanny G. Thank you! Your dedication has real impact in the life of Maggie C. our children. Doreen J. Thank you! Kristen D. Jennifer M. Thank you for all that you do to support research for Chris D. Please juvenile dermatomyositis! Your research helps my daughter live a Dominique C. fuller life! Donna N. Jamie W. Kelly F. Julie G. Here's to 1k! Dominique J. Jessica S. Jm is new to our life but already changing it dramatical-Shannon D. Thank you so much.

ly. Any help in curing it or making it easier is greatly appreciated.

much!!

Kathy U.

Kathy U.

kids PJ K.

Kacie M.

Julie S.

Joni A. John L.

Joey D.

## Brynne M. Thank you for your dedication! We are beyond grateful that your research has 100% provided our child the chance to live her life to the fullest.



Denise R. Grateful for the work you do for all children with JDM but especially grateful for the support you gave my son and our family. Denise K.

Melissa D.

Deana A.

Doreen C.

Dan B. We are hopeful more research can help us fight this deliberating illness! Thank you!

Darlene C. Cure JM!

Daniel G.

Cynthia G. To anyone fighting any type of myositis, You are not in this alone. Thank you for the research being done for the young patients fighting rare diseases.

Terri C.

Crystal H. Never give up!

Chris B.

Courtenay E. My daughter is in remission! THANK YOU

Concepcion P. The current treatments for our babies keep them moving as kids, what's hard is the medicine on their bodies. With more research we can find better medicine

Connie A. thank you curejdm for all the work you've done trying to find a cure, improving treatment options for JDM patients, & bringing together families to support one another with this rare autoimmune disease.

Nicole W. Thank you for all you do

Nicole W. You are not in this fight alone

Charlene G. Thank you! Please continue to work to study Juvenile Dermatomyositis!

Bonnie C.

Cassie S.

Christina H.

Michelle S. The NIH and specifically Dr. Lisa Rider were instrumental in taking care of our daughter Rachel for years when she had severe calcinosis. We are also part of the twin sib study. Thank you from the bottom of our hearts.

Chris M. CureJM is a family. When a disease is rare, you do not realize how many people have this disease. Then you go to a JDM conference, where you see the faces associated to JDM and you see how many children have this disease.

Chloe D. <3

Chelsea B. Thank you for being life changers! It means the world to us parents of a child with a rare disease. It is people like you that give us hope. Thank you will never be enough.

Chelsea B. Thank you for helping change lives! Charles T.

CAROLINE S.

Saulo F.

Carla C. Thank you for all you do to support Cure JM! Carla L. Keep Fighting!

#### Cassie P.

Cassie W. My son has suffered from this rare disease and it would mean so much to have a cure for it. Your time and dedication matters to our family.

Anne L. Thank you! We appreciate all that you are doing! Candice R.

Camille D.

Brynne M. Thank you for your dedication! We are beyond grateful that your research has 100% provided our child the chance to live her life to the fullest.

Stephanie B. Thanks for all your support & dedication for our warriors!

Jennifer B.

Britt O.

Brittany I.

Brittany F.

Brittany T.

Brian K.

Brandy L. Thank you so much for all the research and help you give to JDM patients and parents!

Viridiana R. We thank you and appreciate everything you do with every step my son takes. Thank you.!!

Rebecca M. Our kids need this help!

Beth D. Thank you so much for all that you have done thus far in finding a cure for JDM.

Bobbie B. Thanks for all you do!

Brandi E. Please continue the research that is so important to find a CURE for our precious children!!!

Bianca C.

Chris B. My son has been battling this for 5 years now. Something needs to be done. Everyone says how science has advanced, but in our case there are no answers. We want a cure!!!! Please be diligent in your pursuit.

April M. There are not enough words to express our gratitude for all that you do for our warriors. #cureJM

Alexis C. Thank you. Your work is purposeful and it matters.

Trina A. Thank you everything you do for our kids on this journey to finding a cure!

Anabel N.

Annie N. Thank you for what you do for our rare kid! Cynthia V. Angelique J. Keep going kids! Angie C. Thank you for all you do!

Adrianna N.

Amy B.

Amy S. Thank you for continued research for juvenile dermatomyositis! Raquel A. Hope

### Adam G. Thank you for helping save and improve children's lives!



Amber Z.

Amanda I.

Alyssa Q. Thank you for working toward better treatment and a cure for children like mine, with JDM.

Allison T. Thank you for all of your important work! So grateful! Alexis B. My daughter was diagnosed with JDM at three years old. It's a rare disease that attacks her muscles and the tissues in her body. I appreciate the research that these people are doing, working hard to help others with rare diseases. My daughter could not walk at two years old, had purple rashes that didn't go away and constantly had problems. She was quarantined at a hospital until we found out she was diagnosed with JDM. She has went through so many challenges and because these people had done their research and scientist create these special medicines to help people, my daughter is able to walk and run and play with other kids. She most definitely has had to take medicine everyday of her life and always will. I hope one day these smart and amazing people can help find a cure for our loved ones. Thank you CureJM for all this support and letters they help inspire others and reach my heart and I'm sure many more who have to go through this. Great work everyone!

Alan A. Go CureJM! Deborah C.

Adam G. Thank you for helping save and improve children's lives! Ashley W. Thank you! Andrea B. We love our JDMer Roger K.

## Grandparents

Jose K. Wendy M. Wendy M. Robert W. Lynn N. Thank you for your work critical research, drug discovery and clinical trial breakthroughs for all rare diseases including Juvenile Myositis. Timothy L. Trenna T. These kiddos are so brave! They and this rare disease need and deserve all the attention and support they can get! Spencer Strong! CureJM! Thomas B. Please continue the research into juvenile myositis and help all those affected by this rare disease! Thomas B. NCATS your work in rare diseases DOES matter to me, my granddaughter, and our family!! Terry T. Let's find a cure for these kids! Terry T. Thank you for what you do for our kids, please keep up the great work. Thank you Terry T. Keep up the amazing work .....our kids are super heros! Terry E. Theresa N. Suzanne B. I love someone rare Susan M. We are so thankful for all the research being done to help find better treatments and cure for our kids one day. susan K. Ellen S. Susan S. Thank you for anything, and everything, you do! Susan S. Thank you so much! Sandra K. Thank you for the research on this rare disease. Skip N. Our family appreciates the very important work you do with/for rare diseases such as Juvenile Myositis. Thank you. Sheryl C. To all the children and grandchildren who deserve the best, loving care. Sheryl C. I see my grandson struggle daily when in a flare. He needs to feel well EVERY DAY. That's all I ask for him. Sheila H. Thanks for continued support of Juvenile myosisis! Sheri G. Martha P. Rosalie D. Roberta M. Randy H. Rhonda R. Let's find a cure Randy P. Phuoc D. Phuoc D. Phuoc D. Christine M.

Steve R. Thank you so much from the bottom of my heart. Maureen L. Thank you for working with Cure JM to find better treatments and hopefully a cure for Juvenile Myositis.

#### Maureen F.

Margaret M. Thank for the research on JM going on at NIH. Laurette S.

Mary Z. Thank you and God bless you!

Michael M. Thanks to all who share their time and expertise to find new ways to treat JDM!

Michele C. Thank you for the important work you do for JDM. I am eternally grateful.

Lawrence L.

Helga R. Absolute heartfelt thanks to all who have helped during a heart breaking illness to children, there are no words to express the care & help received for my Grandson! Mark S.

Margaret C. Continue the work of NIH .

Laurel R. With our support, we will find a cure for this disease!! Lori and Joe K. Thank you for all of your work to help JM kids everywhere!

Lori and Joe K. Thank you for all of your hard work in helping JM kids!

Linda B. Please keep the research going - my great granddaughter is in her 5th year with this disease and still not even close to remission.

Lynn J.

Lynn J.

Eloise S. Thanks for all that you do to help combat these rare diseases!

Elisabeth R. Liam is my hero and such a warrior. The strides you are making will hopefully help find a cure once and for all.

LaNae M. Praying for advancement in helping find cure for JM. Love you Gracie

April E. Your hard work to help with treatments for rare diseases really does matter to our family, Thank you!!

Ester K. Hopefully cure will come soon enough.

Susan S.

Susan S.

Kimberly L. Thank you so very much for your past and continuous support to our grandchild and all the affected patients. We truly appreciate everything the NIH does.

Judie D. Thank you!

Joy P.

James H. You are our heroes. James & Rosemary Hower John K.

Joel R. Thanks for your research in rare diseases.

Stephanie B. Anything I can do to help I would be available..

THANK YOU, for all the wonderful work you do.

Rosa N.

Alice C.

Lois F.





Darcy R. My granddaughter was able to change her treatment to a drug she could do at home instead of in hospital IVIG. It has saved so much money and time and she can be at home with family. Much less stress and I believe helps in healing. This because of research being done. Thank you.

Toni G. Keep fighting! One day, we will find a cure! Elinor D. Keep up the great work! Praying everyday for a cure. Thank you for all you've done and continue to do... Elinor D.

Eileen B. We appreciate your work toward finding a cure for JM and other rare diseases.

Daniel S. These children deserve our best efforts at working for a CURE! Cure JM is a wonderful organization putting much effort & monies raised toward research! & filled with those who have the best interest of these children at the top of the list!

Nan S. Keep on looking for a Cure! Cure JM is a wonderful supportive organization to children, parents, grandparents & others! Deborah L.

Deborah L.

Diane P.

Diane P.

Darcy R. My granddaughter was able to change her treatment to a drug she could do at home instead of in hospital IVIG. It has saved so much money and time and she can be at home with family. Much less stress and I believe helps in healing. This because of research being done. Thank you.

Dalene K. Thank you for your hard work and dedication. It is making a difference and giving hope to so many, and is deeply appreciated!

Cyndy P. We are very grateful for all the research that is done by NIH for rare diseases

Colleen S. Keep working on this disease--to wipe it out, especially in our children.

Cheryl J. New and better treatments create a better quality of life for our JM kids. Thank you! Cheryl, grandparent of Kelly (dx at 2 1/2, remission at age 6)

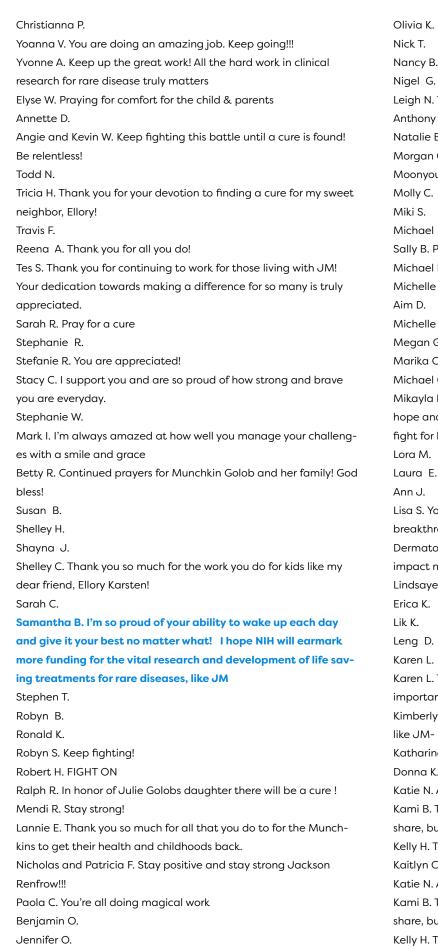
christine b. Thank you for continuing to look for better ways to manage this disease

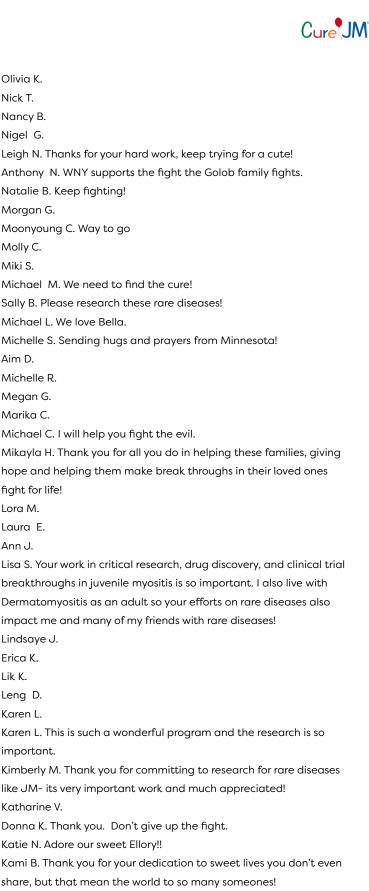
Daphne L. Thank you for all you do to help improve the lives of our "rare" kiddos!

Allison R.

Julie A.

# **Friends**





Kelly H. Thank you for working so hard on a cure!

Kaitlyn C.

Olivia K. Nick T.

Nancy B.

Nigel G.

Morgan G.

Molly C.

Miki S.

Aim D.

Michelle R.

Megan G.

Marika C.

fight for life! Lora M.

Ann J.

Lindsaye J.

Lik K.

Karen L.

important.

Katharine V.

Katie N. Adore our sweet Ellory!!

Kami B. Thank you for your dedication to sweet lives you don't even share, but that mean the world to so many someones!

Kelly H. Thank you for working so hard on a cure!

Jessica K. We are thankful for the work that is being done to support Ellory in her journey with Juvenile Myositis. We will pray for continued progress and funding necessary to make her life as flourishing as possible. CureJM

#### Kaitlyn C.

Jennifer J. We appreciate the team at the National Center for Translational Sciences at the NIH and their work in critical research, drug discovery, and clinical trial breakthroughs in juvenile myositis! Jill R. John-Paul P. Thanks for all you do! Summer R. joanne f. You Got This! Peter and Joanna J. Thank vou! Jeffrey S. Jimm M. My sincere wishes for a quick healer to be found and my nightly prayers for a victim of this horrible disease. Jill M. For Bella Lau You go, girl!!! Keep doing great things! James G. Great work, Liam! John G. Jessica K. Jessica K. We are thankful for the work that is being done to support Ellory in her journey with Juvenile Myositis. We will pray for continued progress and funding necessary to make her life as flourishing as possible. Jennifer P. Thank you for all you do to find a cure for JDM. Janette P. Let's keep after this!! Jane J. I am in awe of the families I have met/heard of who deal with JM with courage, humor, and determination. Gabby F. It is often difficult to understand the challenges we face. But God puts in front of us trials to help us get closer to him and find the powers within us: - The power of resiliency to adapt and never give up. - The power of mindfulness to stay in the present and enjoy every second we are alive. - The power of happiness that protects our minds and hearts. - The power of love that heals our soul. - The power of prayer to remember that God loves us unconditionally and he is always with us. - The power of dreams that sparks our imagination to make the impossible a reality. -The power of life that give us an opportunity to be our best every day. Remember that the power is within you to dream, love, pray, laugh, and never give up. With love, Gabby Franco Lauren G.