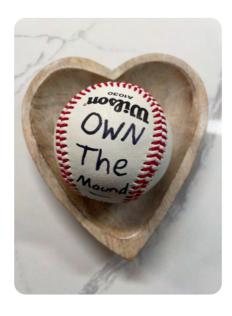


# The Charlie Landers Second Edition Newsletter

Welcome to the second edition of The Charlie Landers Foundation Newsletter!

We wanted to take a moment to wish all of you a very joyous holiday season and happy new year. Thanks to each and every one of you for the ways in which you've made The Charlie Landers Foundation flourish into something we know Charlie is very proud of.



Love, like a great pitch, is the greatest weapon against this disease. That, and the necessary research to strike out Ewing's sarcoma. We believe that love wins. Thanks for being on our team.

We also wanted to take this opportunity to share what The Charlie Landers Foundation has been up to over this past year and all of the good that your dollars have done. Thank you for attending our events, for supporting us and for your tireless energy and enthusiasm.

### \$850,000 Raised Toward Research and Patient Comfort Kits

This year, we've raised over \$850,000 with every dollar going towards research and patient comfort kits. We are comforted in knowing that we have research investigative warriors laser-focused in the fight and dedicated to this cause, to eradicate Ewing's so patient warriors just like Charlie have a fighting chance to live.

### Thank you!

Because of you, we were able to fund 4 high impact grants totaling \$350,000 with more than 500 CL7 patient comfort kits sent nationwide to over 28 hospitals with Ewing's sarcoma populations. Our goal for 2024 is to donate \$400,000 for our next round of funding and get a comfort kit into the hands of every patient diagnosed with Ewing's sarcoma. We can do this, with your help.

As this year comes to a close, we wish you a warm and wonderful holiday season filled with JOY, HOPE and all good things. We hope you always remember to #ownthemound #wintheday #findthejoy

For Charlie, Lisa Landers, President The Charlie Landers Foundation

### **CL7 Grant Recipients**

We hit the ground running in 2023. CL7 awarded and funded our first round of research grants in July. We are tremendously excited and blessed to allocate over \$350,000 to 4 high impact grants in the ongoing search of a cure.

Congratulations to the following researchers and their teams. We are so grateful to them for the critical work that they do to strike out Ewing's Sarcoma. Thanks also to our Medical Advisory Board for their guidance and expertise.

Dr. Kelly M. Bailey/UPMC Children's Foundation \$50,000 Study title: "The role of galectin- 3 in metastatic Ewing Sarcoma"

Dr. David Gordon-University of Iowa, Stead Family Children's Hospital \$69,790 Study Title: "Targeting DNA replication stress in Ewing sarcoma tumors"

Dr. David Shulman- Dana Farber/Boston Children's Cancer and Blood Disorders Center \$130,224 Study Title: "Clinical
Translation of circulating
tumor DNA (ctDNA)
liquid biopsies for
patients with Ewing
sarcoma"

Dr. Jason T.
Yustein/Emory University
School of Medicine
\$100,000

"Study Title: Dissecting and targeting PAK4mediated signaling in Ewing sarcoma development and metastasis"

#### CL7 Pickle Paddle Palooza

We pickled, we paddled, we partied! Thanks to all for partaking in the absolute JOY of our first (what we hope to be) annual CL7 Pickle Paddle Palooza! Heartfelt thanks to the entire staff at the Indian Trail Club as well as all of our volunteers for making this day PERFECTION on every level. This day wouldn't have been possible without our fearless Committee Co-Chairs Andrea Coughlin and Ray Crosta for their tireless efforts in making it a success. Blessed to have Whiskey Helps along for the ride and as always our VP Alison Curcura's decorations! ALL funds raised from this event go to direct support and research to take aim at a cure for Ewing's Sarcoma!! Many many thanks to supporters, friends and family for partaking in this special day- What a community we have.









### **Own the Mound Games**



Charlie's Ramapo High School Varsity baseball team for hosting the very first "Own The Mound Games" in support and honor of Charlie's fervent mission to strike out Ewing's Sarcoma.

4 Competitive games were played with High School scouts on the scene to check out the top talent. All proceeds went to benefit research and to stock and send CL7 patient comfort kits nationwide! [] What a home run!



# The Second Annual Charlie Landers Golf Classic

204 golfers. Laughter, tears, great golf at beautiful Upper Montclair Country Club in Clifton, NJ. Amazing music, special guests and heartfelt speeches. Special thanks to Charlie's NP and Medical Advisory Board Member Jessie Hennessy for sharing few words about Charlie's journey and the critical need for supporting research around Ewing's Sarcoma. This year was about remembering Charlie, Dylan Newman and Lucy Macalusco, two fellow warriors who also lost their battle with Ewing's this year. We were honored to have their parents and dear friends Todd and Tanya Newman as part of this day as well as Adam Macalusco for his bravery in sharing Lucy's journey. The day was about friendships and love that know no end.









# Franklin Lakes 7k Wellness & NYC Central Park Runs

Runners, walkers and a few bikers came out on 7/7 for Charlie's 7k Wellness Run. Starting at Charlie' Rock at Pulis Field, \$7,000 was raised by our 7pm race that evening. Co-Captains Krisi Behrens and Patricia Poppe, Erin Poppe and Annie Landers led the charge.



Thanks also to Dina Robinson, the FLPD and all the wonderful volunteers who made our hometown wellness run so memorable. This year, we looped one of Charlie's War Eagle's baseball fields and felt nostalgic as we "Won the Day" raising money for Ewing's.





Charlie had so much more he wanted to accomplish and all who came out that day as well as those who continued to do their own 7k's throughout July via walking, running, biking or hiking, honored Charlie's wishes and legacy in a big way.





A few weeks later we were back at it but in NYC with a huge outpouring of participants over 140 people! who came out to show their love for Charlie and Davi Perez at our Central Park road race. You couldn't help but feel joyful and smile as you rounded the Central Park reservoir, took in the beauty of the park and just feel the presence of Charlie and Davi. Over \$20k was raised towards striking out Ewing's Sarcoma. Thanks to Morgan Stanley for showing up big time as well as friends and family who got a chance to reminisce and pay homage to our guys. #fordavi #forcharlie #wintheday

### YMCA Scenic Half Marathon



And the running continued into the fall with sunny skies, crisp fall air and happy feet [[[[ Heartfelt thanks to Wyckoff Family **YMCA** Senior **Development Director Nancy** Addis, **Executive Director** Joyce Vottero, the entire staff and volunteers the **Wyckoff** Family YMCA, generous sponsors as well as the runners for a beautiful Franklin Lakes Scenic half marathon and 5k!

Thanks again to CL7 cocaptains and running gurus Krisi Behrens and Patricia Poppe for your words and enthusiasm and big shout out to Ramapo Baseball for manning one of the water stations and for always showing up and being there



The Wyckoff Family YMCA is very special to CL7, it's a place where community thrives and people care and where many happy times were spent and memories made with Charlie. Thank you for supporting Charlie's mission to help raise awareness and raise critical funds necessary to strike out Ewing's Sarcoma.

Last but always first, Thank you Charlie, Dylan Newman and Lucy Macalusco for guiding us today and inspiring us to do better!!! "The team was doing sprints so I sprinted" -CL7

#### CL7 Oktoberfest

It took a team, it took the "A Team"

We threw some heat under the big tent on October 14th!!! CL7 Oktoberfest was a huge success because of our beloved CL7 community near and far. All said and done, about 600 people rallied to strike out Ewing's with approximately \$180,000 raised. Thanks to all of Charlie's special teams representing that night-beloved friends and family, teachers, coaches, generous donors as well as other patient families. Special thanks as always to Charlie's incredible Doctor, Dr. Paul Meyers, Chief of the pediatric sarcoma clinic and vice chairman of clinical affairs at Memorial Sloan Kettering Cancer Center, for speaking about the important need for ongoing research to put an end to Ewing's.

To our MVP Dave Catuogno, thanks for knocking it out of the park with your live appeal.

We line danced with music by the stellar Country Comfort Band, beer stein challenged, reminisced and laughed. So much love. The continued love and support for Charlie is felt and is fueling change for others just like him.





### 2nd Annual Sporting Clay Classic at Hudson Farm

Roughly 80 shooters came together at Hudson Farm on October 19th

to put a target on Ewing's Sarcoma. It was a beautiful fall, blue sky day, filled with love, hope and speeches such as one given by Charlie's Doctor and CL7 Medical Advisory Board member Dr. Michael Kinnaman on the critical importance of fueling research to find a cure for Ewing's. It just takes one breakthrough idea to change the course of this disease. All in! Funds raised from this spectacular day go directly to that critical need.







# The Charlie Landers Foundation Ewing's Sarcoma Grant Cycle Now Open!

Dedicated funds are available for a one-year grant through The Charlie Landers Foundation

(www.thecharlielandersfoundation.org) to support Pediatric Ewing Sarcoma research. This award includes the potential for a second year of funding based on demonstrated progress and the joint approval of the Boards of Directors of The Charlie Landers Foundation.

 $\underline{https://www.the charliel and ers foundation.org/2024-grant-application}$ 



#### We Will Fund:

Innovative and transformative pre-clinical, translational, and clinical research, that has the potential to immediately impact the lives of Ewing sarcoma patients.

**Submission Process and Due Dates Application Deadline: 1/26/2024** 

Announcement of Recipient: 3/28/24 Start of Grant: July 1, 2024

Questions regarding applications should be directed to: <a href="mailto:lisa@thecharlielandersfoundation.org">lisa@thecharlielandersfoundation.org</a>

# Welcome Dr. Ian Davis To Our CL7 Medical Advisory Board



Dr. Ian Davis, MD, PhD, is the G. Denman Hammond Professor of Childhood Cancer and Chief of the Division of Pediatric Hematology-Oncology at UNC-Chapel Hill.Following undergraduate studies in biochemistry and molecular biology atNorthwestern University, Dr. Davis received his PhD from the University of Illinois at Chicago and MD from Northwestern University Medical School.

He then completed pediatric residency and chief residency at Boston Children's Hospital and pediatric hematology oncology training at Dana-Farber Cancer Institute/Boston Childrens. Dr. Davis's lab has had a primary focus on Ewing sarcoma and other solid tumors employing cutting-edge genomic and proteomic techniques in human and animal models. He had had a longstanding interest in the biological mechanisms that underlie the central oncogene of Ewing sarcoma, EWSR1-FLI1.

In addition to his role as a leading researcher, Dr. Davis is the Coleader of theCancer Genetics Program at the UNC Lineberger Comprehensive Cancer Center and is the UNC director for the Unified Program for Therapeutic Discovery in Children fellow training program. His work has earned him recognition, including the Dick Vitale Pediatric Cancer Research Fund All-Start award from The V Foundation in2023, the Martin D. Abeloff V Scholar Award, and the Rita Allen Foundation Scholar award. Dr. Davis's dedication and groundbreaking contributions to childhood cancer research and patient care exemplify his commitment to improving the lives of young patients and their families.

#### **CL7 Patient Comfort Kits**





So, what's in this CL7 comfort kit and why do they matter? Well, when you're stuck in a hospital bed with an IV in your arm and all you want to be doing is live life, it can wear on you both mentally and physically. It's not fair. Nothing about it is. But maybe your day gets a little better when you get a knock on the door or the curtain moves and you see your child-life specialist or NP and they smile at you and come bearing a gift. A gift that is meant to turn your day around or maybe just make you smile and forget for a little while. Who doesn't like a little merch in their life, right?

The CL7 comfort kit includes the things that Charlie loved when he had had "enough" of hospital food and his iPhone. Simple joys, simple things that made it a little better. Charlie's mission was rooted in these kits- "I want everyone who has Ewing's to get a comfort kit. Can we do that?" Yes, Charlie. We can!

For a deeper dive into the kits and who we currently support, please see link: Comfort Kit PDF

### Thank you!

Thanks to the many individuals, sports teams and schools for "owning the mound" and hosting fundraisers this year in support of CL7. Your efforts are greatly appreciated.

MLB Opening Day "Tip of the Cap" Day at FAMS







### **Bella Levison- Doughnate**

New school year, new cookies, unwavering mission!! Bella was back at it baking up big love for CL7 with doughnate now This September, she raised funds for the second time in support of giving to Charlie's mission to help others going through what he did. All proceeds from her delicious cookie orders benefitted CL7. Bless you, Bella!



#### **DON BOSCO for CL7**





BOSCO in the house!!! BIG well done and thank you Jake Long, Conor Kerin, Nicholas and Louis Quartararo ('24) and Harry Long ('27) at the <u>@armorynyc</u>. Running to raise critical funds necessary to strike out Ewing's Sarcoma! Appreciate your friendship, support and tremendous efforts!!!

# Giving Tuesday, November, 28th- A Home Run!!!

A whopping \$7,777 was raised during Giving Tuesday last month. So many rallied to give a bit more to strike our Ewing's. Many first time donors as well as repeat donors gave in ways big and small to help us fund critical research for more curative therapies and options for patients who desperately need more treatments and an ultimate

breakthrough.. CL7 is now a Public Foundation whereby allowing many to be able to give through their employer's matching gift program to support CL7. Every matched gift makes an impact!

Looking to make an end of year donation?

**Donate Now!** 

### CL7 Holiday Reception-Charlie's Team of All Stars

The CL7 Foundation gathered early December in New York City for some holiday cheer and reflection. Medical Advisory Board members Dr. Patrick Grohar from CHOP and Dr. Paul Meyers from MSK Kids addressed the board on the current state of Ewing's sarcoma research and we welcomed Dr. Damon Reed from MSK and Dr. Ian Davis from UNC Lineberger to our team. We are beyond grateful to have these compassionate individuals leading the charge in the fight against Ewing's.



## Upcoming Bergen County, NJ Blood Drive- January 27th 9-2pm



Give the gift of life through the heartfelt act of donating blood in honor of sweet Lucy Macalusco and the Peter T Foundation.

Given the amount of blood transfusions needed during their journey, cancer warriors critically need blood, it's a beautiful way to honor and support them.

**Click Here To See More** 

In early 2024, please check both our social media and website pages

for updates on national blood drive sign ups. There are many ways to give and lend support to your favorite cancer warriors and this is a HUGE one.

### In Memoriam- Lucy Mae Macalusco

Heaven gained a beautiful Angel warrior this past March. Sweet Lucy fought valiantly battling Ewing's and our hearts are broken for her family. Rest easy and know you will always be embedded in the hearts of many ♥□ #welovelucy



20 more comfort kits were sent to the Ewing's warriors at the fabulous Cleveland Clinic under Dr. Peter Anderson's care in honor of Lucy this summer. Then again this fall, more went to her primary hospital Morristown Medical Center where her parents hand delivered the kits. We feel both lucky and honored to get to know her amazing parents Jamie and Adam and have the sacred opportunity to connect, talk and reminisce about our kids and their journeys. Cancer was a small chapter in the story of their BIG, joyful and precious lives.





Everything we do is in honor of patients just like Lucy and Charlie. We need to do better.

# Shop our new winter merchandise!



Winter Merchandise on sale now. This year's haul includes hoodies, PJ bottoms, trucker hats and beanies.

# What's on tap for 2024? Mark your calendars and join us:

- Pickle Paddle Palooza 4/21
- Own the Mound Games Ramapo Baseball Tournament 4/27
- 3rd Annual Charlie Landers Golf Classic- Upper Montclair Country Club 6/19
- Franklin Lakes CL7 7k Wellness Run- 7/7
- NYC Central Park Charlie and Davi Perez Run- Date TBC
- 2nd Annual CL7 Oktoberfest 10/19
- 3rd Annual Sporting Clay Classic at Hudson Farm- 11/7

"Never Give Up Because Your Miracle Could be Right Around the Corner"







#### **The Charlie Landers Foundation**

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