2021 ANNUAL NEWSLETTER

ECD GLOBAL ALLIANCE

Supporting those affected by Erdheim-Chester Disease worldwide

The ECD Global Alliance is dedicated to the awareness, support, education, and research related to Erdheim-Chester Disease (ECD). The organization works with the global community to accomplish its mission in supporting those suffering with ECD and other rare adult histiocytic disorders.

ECD Global Alliance is a 501c3 patient advocacy group supporting patients living with Erdheim-Chester Disease.

BOARD OF DIRECTORS

Since its inception in 2008, countless donors, volunteers, medical professionals, and supporters have made the ECDGA what it is today. Thanks to the leadership of our boards, patient support and research efforts have created a community filled with hope. The ECDGA is very fortunate to have the Board of Directors and Medical Advisory Board help lead the organization into the future.

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MEDICAL ADVISORY BOARD

The medical professionals that make up our MAB are dedicated clinicians and researchers that contribute to the organization's physician awareness and collaboration initiatives, as well as advise and lead the ECD Research Grant Program.

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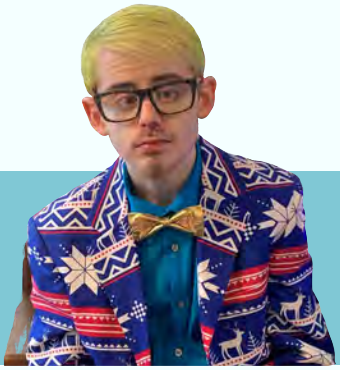


Noah Finds Courage & Purpose

A story of a young rare disease patient fighting over a decade for the answers to his illness.

Erdheim-Chester Disease most commonly affects adults between 40 and 70 years of age. However, as the disease becomes more well-known, it is sometimes discovered earlier in the life of a patient. Although this may be good news for those searching for a diagnosis, it also exposes the fact that physicians are seeing ECD patients that are affected much earlier in life.

This is certainly true for the young Noah Barone from Kentucky. **Now at the age of 22, he has battled the disease for at least 16 years.** At the very young age of about six years old, Noah began to have bulging eyes, crossed eyes, and very bad headaches. The concerned parents brought him in for a consultation with an eye specialist that deemed the abnormalities as “lazy eye.” Thankfully, a family friend that is a doctor commented that this was more than a lazy eye and recommended an MRI test to see what was going on. From this, the first clue that something was seriously wrong emerged; they found lesions on his brain.

The next step for his care team was to call a neurologist at a local hospital for further testing. Surprisingly, ECD was mentioned, but because of his age and some tests that could not be performed at the time, they ruled it out. Instead, the doctors performed biopsies and came back with a diagnosis of Inflammatory Pseudotumor of the brain.

“I remember the first time I was sent to the doctors at the hospital when my MRI came back showing lesions. There weren’t any beds for me at the hospital, we had to check-in through the ER. My mom and I sat in a chair for hours waiting to be able to get a room. I fell asleep with my head on her. **I was only 6-7 years old. Little did I know it would bring this ECD journey**,” Noah recalls. Mom and Dad were a bit more aware of what was going on, “The only word that comes to mind is ‘scared’ when we first heard ‘lesions in the brain.’ After that there was no time to think about it, we went into fighting it and praying for guidance.”

After 12 long years of not knowing the cause of these lesions and his pain, an answer finally came from a specialist in New York City at the cancer center Memorial Sloan Kettering. This is one of the most highly recognized ECD Care Centers in the US, led by a neurologist, Dr. Eli L. Diamond who delivered the diagnosis to the family in 2017. At this point, he was able to join a drug trial for ECD patients, stopping the disease from spreading and affecting his body even further. **“[The] ECDGA is how I was able to find my ECD expert and get on a clinical trial that saved my life.”**

Geneva, Noah's mom, recollects how the possibility of an ECD diagnosis came about. "The doctors kept doing different tests and somewhere along the lines, ECD came into the picture. My husband and I found the [ECD Global Alliance] website and something drew me to Dr. Diamond so I emailed him with questions. He emailed me back and we had another biopsy done and sent to him. Where he found ECD markers to confirm it and we went to see him July 2017."

Continued on page 4.

Now he fights the damage that the disease created in his body during the long wait for answers.

Due to the rarity of ECD, which has been suggested to affect perhaps 2,000 people in the world, it is not uncommon for a patient to go undiagnosed for many years, (an average of 5 – 7 years has been noted in medical literature). Though Noah was on the unfortunate end of this spectrum, he noted that **his doctor never gave up**. As Noah's most memorable care member, Dr. Salvatore Bertalone helped Noah and the family to stay positive and encouraged them to continue fighting. "*He was always fighting for me and never gave up on me*," says Noah. "*Even though we didn't have a name for what I had then, he was able to treat me and keep me going until we found out what I had and how to treat it.*"

Despite what Noah was facing as a teenager, he found a way to help others! He and Dr. Bertalone created a fundraiser together named "Noah and Dr. B" that helped raise funds for other kids and families that had cancer. This fund helped parents with costs associated with travel, gas, and food; and it helped the clinic with entertainment costs and IV pumps. Noah has now moved his charity over to helping Dr. Diamond with ECD research!

"It is a tremendous honor when patients like Noah raise funds for ECD research. We are making the best possible use of this support to help ECD patients have the best possible outcomes," Dr. Eli Diamond adds.

Salvatore Bertolone Jr., M.D., talks with 16-year-old Noah as parents Geneva and Mike Barone stand by and listen in.

"**ECD has taken away my independence.** Even though I can't do everything myself I stay focused on what I can do, which is my outlook on life with others. I never stop trying and I wake up and say 'Life is worth dressing up for.' So, I dress up and am thankful for the day."

Noah enjoys music and fashion! "I try to go to concerts as much as I can. (Covid 19 has put a hold on that.) My best memory is going to ELO with my aunts in 2019."

Noah wants readers to know, especially doctors, "**Any age can have ECD.** Also, if you don't know, contact the experts on ECD to help the patient with a game plan as fast as possible. The faster you start treatment the least damage it can do."

Noah also shares a message to his peers in the fight against ECD, "**Don't give up, keep fighting.** The treatments they have now work and will make a difference in your life. Don't be afraid to ask questions. Stand up for yourself."

Noah, of course, is hoping one day for a cure. And we are right there with him!

By Jessi Corkran
with the help of Mom & Caregiver, Geneva Barone

ECD PATIENT REGISTRY

FUNDED BY THE ECD GLOBAL ALLIANCE

The Erdheim-Chester Disease Registry, led by Memorial Sloan Kettering Cancer Center (MSK), unites leading researchers in building a comprehensive database about ECD. Investigations into what kinds of health problems are caused by ECD, what happens as a result of different treatments for ECD, and how ECD affects people's physical health, psychological well-being, and overall life circumstances. The investigators also want to learn how health, symptoms, and overall quality of life change over time for people with ECD.

The ECDGA is committed to continuing the registry's management and funding so we can continue the growth of invaluable information this database will provide to the community. Currently, approximately 160 participants have been enrolled.

To join the Registry, please email neuecdregistry@mskcc.org or call 1- 212-610-0720. The Principal Investigator for the ECD Registry is Dr. Eli Diamond, who can be reached at diamone1@mskcc.org or 1-212-610-0243.

JOIN THE REGISTRY

LATEST REPORT

ECD CARE CENTER NETWORK

CARE CENTER NETWORK

The ECD Care Center Referral Network is the backbone of quality care for ECD patients. The ECDGA works with leading physicians to build a solid path for institutions willing and able to help these patients find quality care. These centers of care are available to help all ECD patients and the physicians will work with a patient's local medical team.

Patients and local doctors are encouraged to reach out to the contacts at one of these 35 centers for help in diagnosing, treating, and monitoring ECD patients.

EDUCATION & SUPPORT FOR EACH MEMBER

The ECDGA works to identify ways to enhance the exchanges among patients, caregivers, and physicians throughout the year, creating a strong, encouraging network.

FOR THE FAMILY

The ECD community will finally be brought together again for the 8th Annual Patient & Family Gathering on April 7-8, 2022 near the Mayo Clinic in Rochester, MN. Find the details and registration link here.

PATIENT GATHERING

2022 CHAT SESSIONS

Patients & Community:
Monthly meetings will continue for face-to-face peer social interaction.

Caregivers:
Monthly to bi-monthly meetings for those caring for an ECD patient.

Grieving:
This support group is available to all family members that have lost someone to ECD.

International:
Spanish and French sessions will be available. More languages will be added as soon as possible.

CHAT SCHEDULE

REGIONAL CONNECTIONS

Want to meet other families close to you?
Contact our team to request an introduction!

FOR THE DOCTORS

On April 6-7, 2022, the Medical Symposium will be held at the Mayo Clinic in Rochester, MN. Presentations are technical in nature and best suited for medical professionals and researchers. To view details, register, or submit an abstract follow this link.

MEDICAL SYMPOSIUM

View the 2021 Virtual ECD Medical Symposium!

LATEST MEDICAL RESOURCES

New Pathology Guide!
Erdheim-Chester Disease: An Algorithmic Approach to a Diagnosis

NCCN Clinical Practice Guidelines
Histiocytic Neoplasms, Version 2.2021

Survivorship Issues in Adult Patients With Histiocytic Neoplasms

Educational webinars will be made available for all community members throughout the year! Stay tuned for your invitations.

VIEW PAST WEBINARS

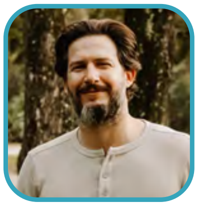
VOLUNTEER APPRECIATION

See how you can help in 2022!

What happens behind the scenes?!

Volunteers are the lifeblood of the organization, supporting the community and contributing approximately 1,000 hours of service to numerous essential programs and functions. We want to recognize a few volunteers as outstanding examples of dedication and passion for the community. Thank you to all of our volunteers for making the future brighter for ECD families!

"The ECD Global Alliance is truly a blessing and has been such a huge part of the lives of our family for many years. It is imperative that we raise awareness about ECD and all of the support that the Global Alliance offers. Creating videos happens to be my passion and that's why I'm grateful for the opportunity to volunteer with the ECDGA. It's my hope that the content we create will help to educate, inform and raise the general publics awareness of ECD and the amazing team that has dedicated their lives to the organization."



Kevin Thomas

VIDEO PROJECTS

Chris Evans

MEDICAL PROFESSIONAL OUTREACH

"My sister, Raina, passed away from a malignant histiocytic disorder that was in the same family of diseases as ECD. While it was not the same disorder, the ECDGA still provided so much help, resources, and encouragement that I really wanted to give back to the ECDGA and honor my sister's memory. My sister had inspired me to change careers to medicine and help others. My experiences with the ECDGA have been rewarding and I look forward to continuing to be a part of the battle against rare cancers."

This year, when Rebecca learned that we needed help with translating materials into other languages, she got to work immediately! Thanks to her leadership and tenacity, the ECDGA will be able to offer educational brochures in other languages. Pictured with her on the right is Magali, who recently completed the Spanish version of our brochure. *"She was so happy to be able to help with the translation - and it really gave her purpose to know what she did to help and that she was very much appreciated - she will be 81 in January!"* - Rebecca

Rebecca Winthrop & Magali Alvarez

CHAT MEETING LEADERS

Julie Jones

Dr. Julio Hajdenberg

Fr. Charles Balnaves

Joe Gauzens

Pascale Baugnet

Elaine Sanchez

YOUR DOCTORS VOLUNTEER, TOO!

In between patient care and research, your doctors are serving the ECD community even further by creating educational materials, providing educational presentations, collaborating with other researchers and clinicians, consulting on complex cases, co-hosting events and webinars, managing the grant and care center programs and so much more. These are just a few of your supporters. Please thank your care team for going above and beyond!

Dr. Eli L. Diamond
Dr. Gaurav Goyal
Dr. Ronald Go
Dr. Mark Heaney
Dr. Aishwarya Ravindran
Dr. Benjamin Durham
Dr. Jennifer Picarsic
Grant Review Board

Ginny Brand

BOOKKEEPING

DOUBLE YOUR DONATION

$80,000 MATCHING CAMPAIGN
ENDS DECEMBER 31

Thanks to an **$80,000 matching gift** from a group of generous ECDGA Board members and benefactors, your donation's impact on our critical work will go TWICE as far in 2022. Please consider sending your year-end giving amount today!

> *We had good doctors here, but they weren't connected. The ECD Global Alliance, which is dedicated to research, awareness, support, and education, helped us coordinate our doctors and we were able to go to the NIH and have further testing done. And thanks to the doctors here and the ones that volunteer and work with the Alliance my daughter is doing very well today. And that is why I give to the ECD Global Alliance."*
>
> \- Sherry, ECD Parent

★ OUTSTANDING DONORS

The ECDGA is extremely appreciative of each and every one of our donors and every dollar they are able to contribute. We would like to recognize our major donors this fiscal year for their part in making the ECDGAs programs and services possible! THANK YOU!

The Larry Hobson Family
Bob & Janet Froetscher

LeAnn Pope & Clyde S. McGregor
Lee & Barbara Crump

Bill & Tracie Frame
Steve & Janis Ban

62
COUNTRIES SERVED

768
FAMILIES SERVED

$800,000
RESEARCH FUNDING GRANTED

35
CARE CENTERS OF EXCELLENCE

Thank you for your support to help the community continue on the path to a cure!

WHAT YOUR GIFT PROVIDES:

EDUCATION

RESEARCH

SUPPORT

Checks Payable to:
ECD Global Alliance
P.O. Box 775
DeRidder, LA 70634

PayPal Giving:
paypal.com/us/fundraiser/charity/1903749

Online:
www.FundECD.org

In Memory of

our members lost in 2021.

Over the past decade, the prognosis of ECD has improved tremendously. Patients have lived for more than a decade while managing the disease. A strong support system and the willingness to fight for the care you deserve can carry a family through many hurdles. We are honored to be a part of their journey. Thank you to the families that have agreed to recognize their loved ones with our community.

Rita Porterfield

May 20, 1950 - March 8, 2021

Bengt Thornberg

September 29, 1968 - April 4, 2021

Walter Comer

May 29, 1961 - April 27, 2021

Pamela Shirley

August 10, 1944 - May 11, 2021

Craig Beattie

March 25, 1959 - September 3, 2021

A MESSAGE FROM OUR STAFF

Every day I am humbled by the courage and passion of the ECD community. I see patients, caregivers, medical professionals, researchers, volunteers, and donors who come together in ways that help not only individuals but the community as a whole. Together we will continue the quest to obtain earlier diagnoses and treatments for all, as we search for a cure.

Kathy

Kathleen Brewer | President
+1.337.202.5200 x102
Kathleen.Brewer@Erdheim-Chester.org

It is exciting to see the ECD Global Alliance progressing each year! As we continue to increase awareness and support more families, we can't help but feel hopeful about the shining light for our path towards a cure. We are ready for a new year of hope and accomplishments with each of you, and I am honored to be a part of the journey.

Jessi

Jessica Corkran | Executive Director
+1.337.202.5200 x100
Jessica.Corkran@Erdheim-Chester.org

Renita Page | Donor Relations/Database Management

It is such an honor to be able to work with the ECDGA community. It has been a pleasure to meet so many of you during this past year through email and Zoom. Feel free to reach out to me at any time concerning your donations. Again, I look forward to meeting some of you in person at the annual event in April.

Welcome our new Patient Navigator Administrator - **Belinda Cobb**

It's a privilege to join the ECDGA team. I find it very encouraging and hopeful to see how the organization is loyal and so dedicated to helping the ECD Community. I am honored to become part of such a noble cause. 'You treat a disease, you win, you lose. You treat a person, I guarantee you, you'll win, no matter what the outcome.' -Patch Adams

THANK YOU!

We are grateful for your loyalty and dedication to those fighting Erdheim-Chester disease every single day. As we embark on another year together, we hope that you find inspiration, support, and hope in our services and within your community of peers.

THE ECD GLOBAL ALLIANCE IS HERE TO HELP

WWW.ERDHEIM-CHESTER.ORG
SUPPORT@ERDHEIM-CHESTER.ORG
1.337.202.5200