

CASTLEMAN DISEASE COLLABORATIVE NETWORK

2021-2022
COMMUNITY UPDATE



OUR MISSION

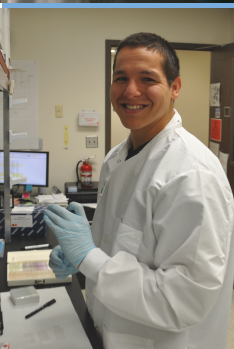
The Castleman Disease Collaborative Network (CDCN) is a global initiative dedicated to accelerating research and treatment for Castleman disease (CD) to improve survival for all patients with CD. We work to achieve this by facilitating collaboration among the global research community, mobilizing resources, strategically investing in high-impact research, and supporting patients and their loved ones.



Biobank



CDCN Team



Patient & Loved One Summit



“

I'm a strong warrior, wife, mother, grandmother and more. UCD and other autoimmune diseases do not define me! Looking forward to new research.

DEBBIE HINKLE
UCD PATIENT

Rare Is *Proud*

“

Can't wait to knock the Castleman's out of the park!

JOSEPH KOSLOWSKI
UCD Pediatric Patient



Penn Orphan Disease Center Million Dollar Bike Ride

Rare is *Many*, Rare is *Strong*, Rare is *Proud*!

DEAR CASTLEMAN DISEASE FAMILY

For me, the fight against Castleman disease is personal.

I am a physician, who in my third year of medical school, as I was training to become an oncologist in memory of my mom, became critically ill. I am a Castleman disease patient who has experienced five deadly bouts of multi-organ failure, with my last rites administered to me when my doctors thought I would not survive. I am a researcher, leading the Center for Cytokine Storm Treatment and Laboratory at the University of Pennsylvania. And I am an advocate who has had the honor of working with hundreds of patients, physicians, researchers, and supporters over the last decade to advance research and treatment for patients with Castleman disease (CD).

While I have endured multiple life-threatening relapses, it is because of the global CDCN community and promising research that I am more confident than ever our work will extend my life and the lives of thousands of others. We now know that siltuximab works for approximately one-third of patients with my subtype, and the drug I discovered and utilize in my own treatment—sirolimus—likely helps a small fraction of patients who do not benefit from siltuximab. Still, more than half of patients with CD do not have an effective treatment to control their disease and save their lives.

To use a football metaphor, we were backed up to our own goal line and the clock was ticking down when the CDCN was established a decade ago—no diagnostic criteria, no treatments, no guidelines, no registries, no biobanks, no organized researcher or patient communities. Through the hard work of so many and with your support, we are now at midfield. And we will not stop until we have identified lifesaving treatments for every patient with CD.

When I think back to the months I spent laying in the ICU and wanting to give up so many times, I never could have imagined I would live this long and be able to work with all of you to advance research. Still, despite our extraordinary progress, much work remains. Better treatments and cures are urgently needed.

Please join us as we continue developing a roadmap to cure CD and other rare diseases. We invite you to learn more about how your investment in the CDCN will help us turn promising research into effective treatments and permanent cures.



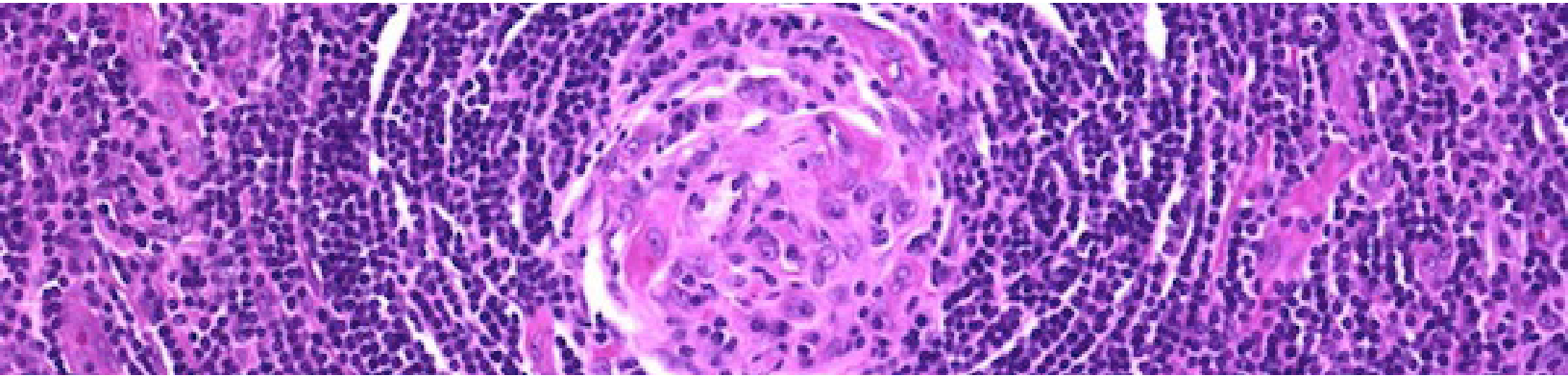
Sincerely,

A handwritten signature in black ink that reads "David Fajgenbaum". The signature is fluid and cursive, with the first name and last name clearly legible.

David Fajgenbaum, MD, MBA, MSc, FCPP
Cofounder and President, CDCN
Assistant Professor of Medicine, University of Pennsylvania

CASTLEMAN DISEASE

A Group of Inflammatory Disorders



Every year, thousands of patients suffer from one of the three debilitating forms of Castleman disease (CD). It can be difficult to diagnose, as CD is both a rare disease and an imitator of many other diseases. Patients with CD can exhibit the same symptoms as some cancers and autoimmune diseases, and due to these complexities, physicians often need to rule out many other diseases before CD is suspected.

SUBTYPES OF CD

1. UCD

unicentric CD

2. HHV-8+MCD

HHV-8-associated multicentric CD

3. IMCD

HHV-8-negative/idiopathic
multicentric CD

4,300-5,200

NEW CASES PER YEAR

CD is a rare disease, but it does not discriminate—it can occur in people of all ages and genders. In the US, there are an estimated 4,300 to 5,200 new cases diagnosed each year.¹



Katie, UCD Patient



David, HHV-8+MCD Patient

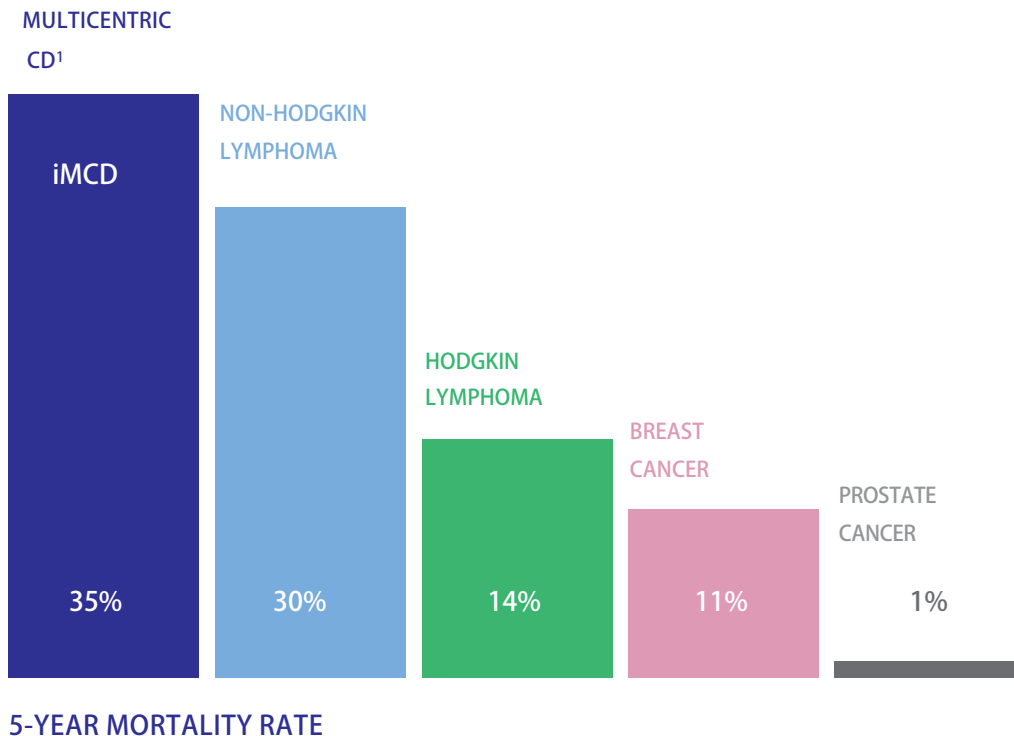


Gary, iMCD Patient

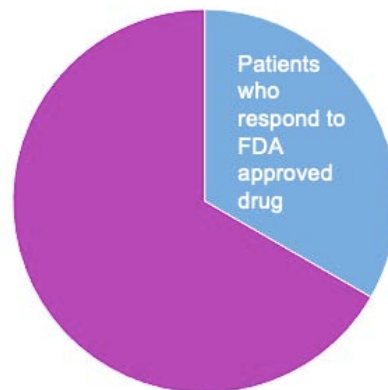
1. Dispenzieri A, Fajgenbaum DC. Overview of Castleman disease. *Blood*. 2020 Apr 16;135(16):1353-1364. doi: 10.1182/blood.2019000931. PMID: 32106302.

AS DEADLY AS CANCER

Approximately 35% of patients with iMCD will die within five years of their diagnosis. This is greater than lymphoma, breast cancer, and prostate cancer. Many patients receive an inaccurate diagnosis of lymphoma before a correct diagnosis of Castleman disease is made, and are temporarily relieved they do not have cancer, only to find out that CD is worse. Part of the issue is that there are limited options for treatment, with only one FDA-approved drug currently available to treat CD. The CDCN is laser-focused on finding more options for patients who do not respond to first-line therapy.



TWO THIRDS
OF PATIENTS DO NOT
RESPOND TO THE ONLY
FDA-APPROVED DRUG
FOR CASTLEMAN DISEASE



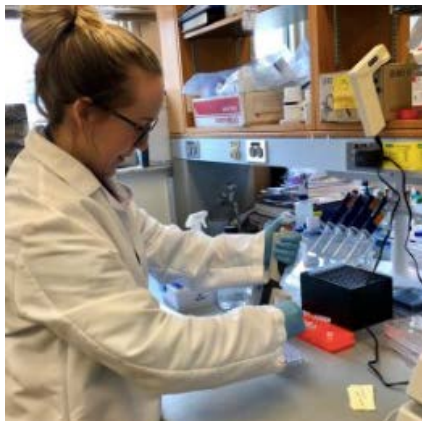
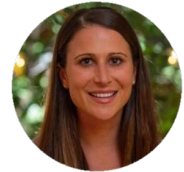
1. Dispenzieri A, Armitage JO, Loe MJ, et al. The clinical spectrum of Castleman's disease. Am J Hematol. 2012;87(11):997-1002.

OUR PURPOSE

The Castleman Disease Collaborative Network strives to advance the discovery of breakthrough immune-targeting therapies to cure CD and related conditions. We focus on bringing together an entire community of physicians, researchers, patients and loved ones to collaboratively find a cure. We are proud to support cutting-edge research that is advancing the treatment of this disease on a global scale.

"We work to create a world where every patient with CD has an effective treatment or cure that extends their survival and improves their quality of life."

Mary Zuccato, Executive Director, CDCN



OUR WORK CAN HELP TO BETTER UNDERSTAND THE IMMUNE SYSTEM, BROADENING OUR IMPACT ACROSS OTHER DISEASES

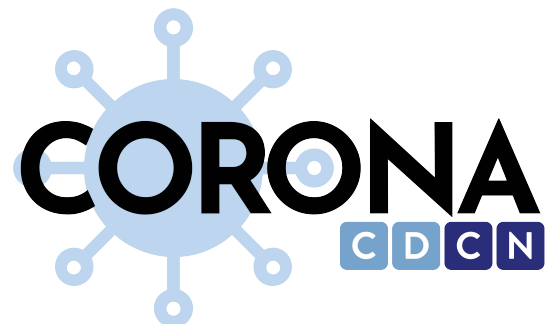
A healthy immune system involves a complex and interconnected network of cells and inflammatory proteins called cytokines, which signal for the immune system to become activated when needed. Lymph nodes are the homebase for immune cells to communicate with one another and coordinate their attack on foreign invaders.

In CD patients, these inflammatory cells become activated and produce excess cytokines, particularly Interleukin-6 (IL-6). The excess cytokines can lead to flu-like symptoms, lymph node enlargement, and dysfunction of vital organs including the liver, kidneys, and bone marrow.

CASTLEMAN DISEASE AND COVID-19

Given the global crisis occurring due to COVID-19 and the urgent need to identify effective therapeutics, and the heightened risk of COVID-19 to Castleman disease patients and others with immunological disorders, we have joined the fight against COVID-19, while maintaining focus and efforts on our other high-priority studies. CD patients experience a cytokine storm inside their bodies, and the CDCN has researched the cellular level of the immune system when these cytokine storms occur. The answer not only informs future potential therapies for Castleman disease, but may also provide new insights into why similar events take place in COVID-19 patients.

By utilizing our experience with drug repurposing, we have created CORONA, now the world's largest database of COVID-19 treatments. It covers more than 400 treatments reported to have been administered to over 340,000 patients, helping researchers identify and prioritize promising treatments for well-designed clinical trials, and to inform patient care. We hope our work helps physicians treating COVID-19 patients to improve outcomes.

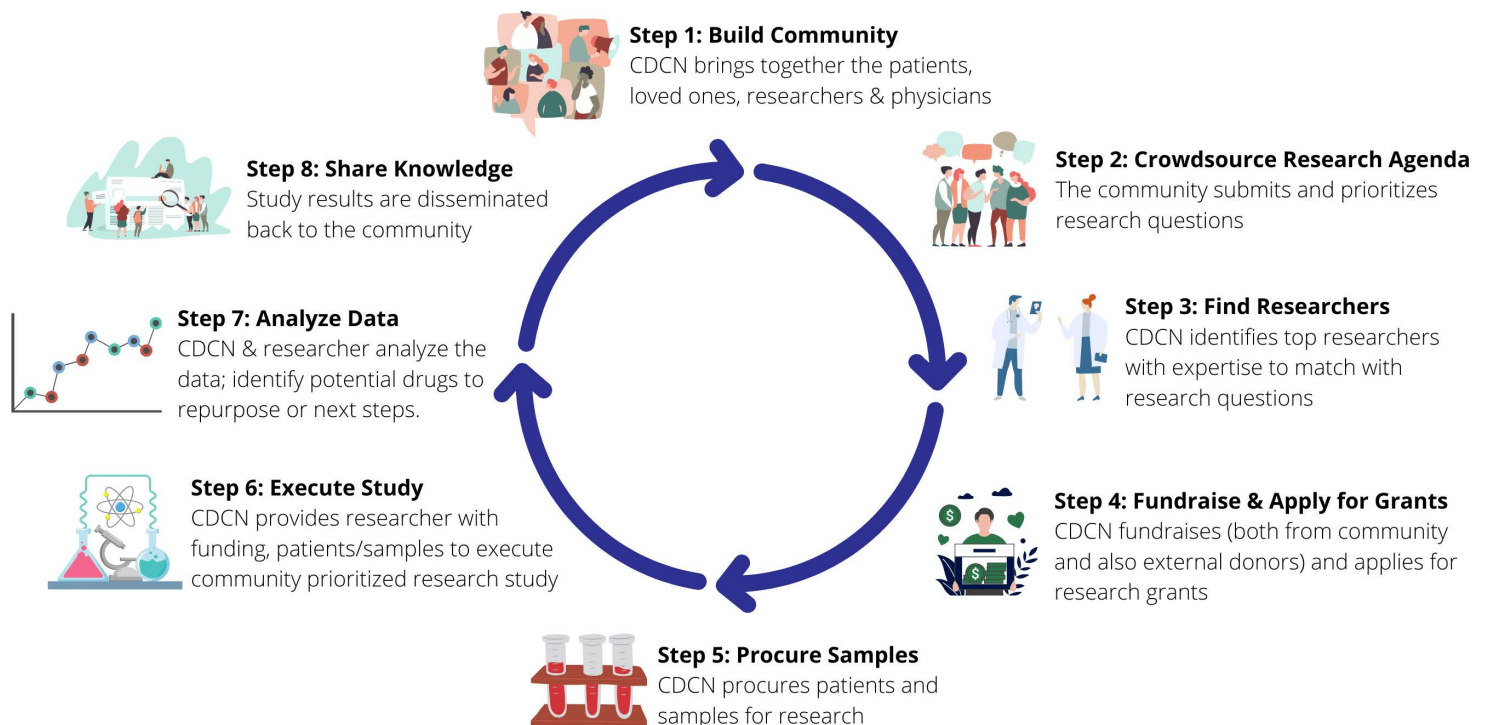


THE COLLABORATIVE NETWORK APPROACH

The traditional funding models for disease research are not as effective when applied to rare diseases. When the CDCN was founded, we knew there could be a better approach to find cures quicker and with less funding. So, we spearheaded a novel strategy for advancing biomedical research—the Collaborative Network Approach.

At its heart, the Collaborative Network Approach leverages and integrates the entire community of stakeholders—patients, physicians, and researchers—to identify and prioritize high-impact research questions. The Network then recruits the most qualified researchers to conduct these studies.

In parallel, patients are empowered to fight back by supporting research through fundraising, and by providing their biospecimens and clinical data. This approach democratizes research, allowing the entire community to identify the most clinically relevant and pressing questions. Any idea can be translated into a study, rather than limiting research to the ideas proposed by researchers in grant applications.¹



The Castleman Disease Collaborative Network has partnered with the Chan Zuckerberg Initiative to bring our model to other rare disease organizations as a guide to find cures more quickly.



There are over 7,000 rare diseases affecting 30 million Americans.

95% of these rare diseases do not have a single FDA-approved therapy.

1. Zuccato, M., Shilling, D., & Fajgenbaum, D. C. (2019). The Collaborative Network Approach: A model for advancing patient-centric research for Castleman disease and other rare diseases. *Emerging Topics in Life Sciences*, 3(1), 97–105.

CROWDSOURCING RESEARCH



Step 2 in the Collaborative Network Approach is crowdsourcing a research agenda. Integral to our success in understanding CD is this innovative model to conducting research, which leverages the power of the entire CD community. This allows for contributions from diverse perspectives and results in unique research questions, which can direct more impactful research.

In 2021, our team engaged patients, loved ones, physicians, and researchers in the All In Movement (AIM) to gather their perspectives about the most important questions we need to answer about CD.

Our community contributed important questions, prioritized them for review, then collaborated with the CDCN Scientific Advisory Board to generate and prioritize the most impactful research studies. We are in the process of recruiting the most qualified researchers to conduct these studies and raising funds to execute the studies.

LEARN MORE at
cdcn.org/research-pipeline

"AIM is one of the most important ways the CDCN operationalizes its commitment to keeping patients at the center of everything that we do."



Alexis Phillips, Former Biomedical Leadership Fellow and AIM Project Lead, CDCN



CSTL: CASTLEMAN DISEASE CENTER AT THE UNIVERSITY OF PENNSYLVANIA

The mission of the University of Pennsylvania's Center for Cytokine Storm Treatment & Laboratory (CSTL) is to conduct groundbreaking translational research on Castleman disease, COVID-19, and other cytokine storms to discover novel diagnostic biomarkers and therapeutics, identify optimal treatment approaches, and provide world-class patient care. Established by CDCN cofounder Dr. David Fajgenbaum, the CSTL is the first center of its kind, integrating exceptional clinical care and clinical trial opportunities with basic, translational, and clinical research. Through this centralized model, scientific research and patient care occur hand-in-hand in a shared environment, enabling the critical research we conduct to be closely informed by the patient experience. Here, scientists interact directly with patients, and patients are easily able to provide blood and tissue samples to our research lab. This unique, integrated approach allows researchers to recognize and address the most pressing needs of the community, and move expeditiously and purposefully toward new discoveries. And it offers more deliberate and meaningful care for patients. Simply put, sharing one mission and one team makes both science and patient care better. The CSTL comprises several immunology researchers at various stages of their careers, who dedicate their time and resources to better understanding and treating Castleman disease. Following is a brief overview of just a few of our experts and their work.



UNIVERSITY OF PENNSYLVANIA RESEARCHERS

[Joshua Brandstadter, MD, PhD, MSc](#), is a physician-scientist exploring if stromal cells—cells that form the structure of lymph nodes and control the immune system's white blood cells—are causing the inflammation in Castleman disease. He has been awarded the Doris Duke Charitable Foundation Physician Scientist Fellowship in support of this work. Dr. Brandstadter also cares for patients with CD.

[Michael V. Gonzalez, PhD](#), is a trained geneticist and bioinformatics scientist who is utilizing novel technologies to gain insights into the genetic and cellular architecture of Castleman disease. His work includes exploring genetic susceptibility, and dysregulated cellular and functional pathways in CD patients, with the aim of identifying and developing precision therapeutics.

[Melanie Mumau, PhD](#), is an experimental immunologist looking to identify pathways and cell types that are dysregulated in Castleman disease. Her current projects aim to identify new disease markers that can be utilized to better diagnose patients, uncover cellular mechanisms of disease, and test candidate drugs. One of her recent discoveries is currently under active investigation.

LEADERS AMONG OUR GLOBAL RESEARCH NETWORK



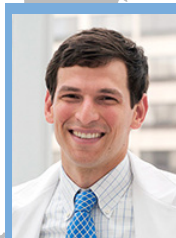
Sudipto Mukherjee
Cleveland, OH



Megan Lim
New York, NY



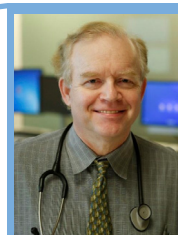
Alexander Fossa
Oslo, Norway



David Fajgenbaum
Philadelphia, PA

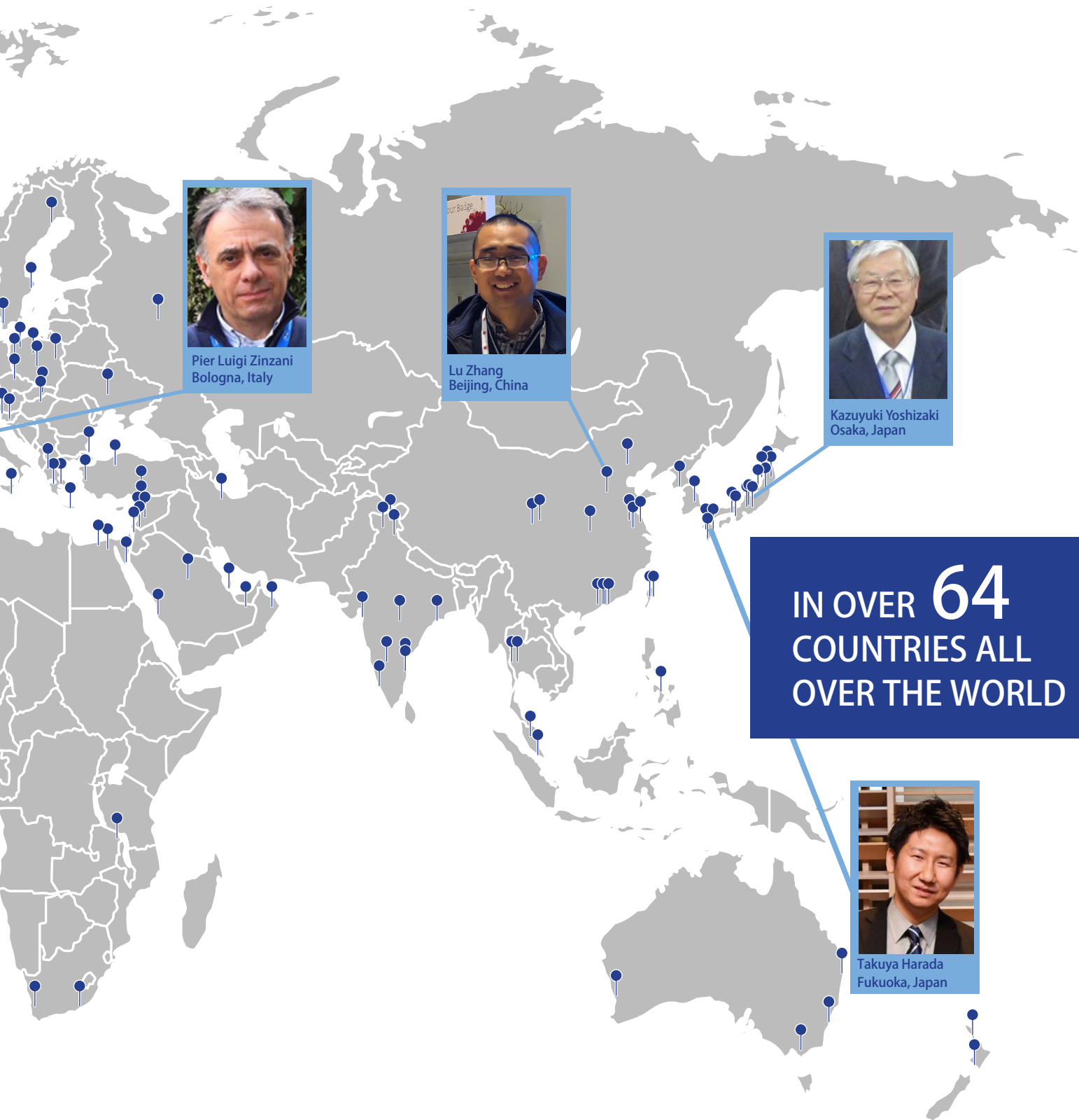


Thomas Uldrick
Seattle, Washington



Frits van Rhee
Little Rock, AR

MORE THAN **800**
CD RESEARCHERS
AND PHYSICIANS



RESEARCH FOCUS AREAS

The causes of Castleman disease are still unknown, but the CDCN's global network of physicians, scientists, and patients are making steady progress in revealing the framework and components of this disease. We will continue to find better treatments and diagnostic tests, and ultimately, save the lives of Castleman disease patients around the world.

What does a patient with Castleman disease experience?

Symptoms of CD include enlarged lymph nodes, flu-like symptoms such as fever and fatigue, skin rash, numbness in the hands and feet, anemia, elevated C-reactive protein levels, very low or very high platelet counts, kidney dysfunction, liver dysfunction, elevated antibodies in the blood, and the accumulation of fluid.

What is the cause of Castleman disease?

In a healthy body, inflammatory proteins called cytokines are released when an infection is detected, returning to normal once the infection subsides. In CD patients, there is an excessive release of cytokines for unknown reasons, causing immune cells to multiply and leading to symptoms. We suspect this is caused by an inherited genetic mutation, a genetic mutation acquired during the course of life, autoimmune mechanisms, and/or an unidentified infection.

How is Castleman disease diagnosed?

CD can be difficult to diagnose, as it is both a rare disease and an imitator of other diseases. Often, other possibilities need to be ruled out before CD is suspected. CD is currently diagnosed by clinicians and pathologists who review lymph node biopsies, blood work, and imaging to determine the likelihood of CD. But there are no definitive tests and diagnosis relies on subjective assessment. We are working toward identifying a more objective approach to diagnosis that would involve specific tests.

What goes wrong in the immune system?

In CD, immune system hyperactivation leads to the release of cytokines. We do not yet know which immune cells are responsible for prompting this hyperactivation. Early research findings suggest that T lymphocytes, B lymphocytes, and follicular dendritic cells may be playing important roles in the onset of CD. We do know a few cytokines that play an important role in CD, such as Interleukin-6, but we suspect other cytokines may also be involved.

What treatments are most effective?

While there are currently a few treatments that are helpful for CD patients, including one FDA-approved drug for idiopathic multicentric CD (siltuximab), these treatments do not help every patient. We are working diligently to find new and more effective treatments for CD patients who are not benefiting from existing options.

HIGHLIGHTS OF KEY PUBLICATIONS

The CDCN quickly shares our research findings with the entire medical community through various journals. Following are a few highlights of published articles in 2021 and 2022.

Blood Advances, September 2021

Discovery and validation of a novel subgroup and therapeutic target in idiopathic multicentric Castleman disease

Wiley Hematological Oncology, January 2022

Bone marrow findings of idiopathic multicentric Castleman disease: A histopathologic analysis and systematic literature review

Blood, March 2022

A prospective, multi-center study of bortezomib, cyclophosphamide, and dexamethasone in relapsed/refractory iMCD

Haematologica, April 2022

The lymph node transcriptome of unicentric and idiopathic multicentric Castleman disease

Wiley Hematological Oncology, April 2022

Increased mTORC2 pathway activation in lymph nodes of iMCD-TAFRO

British Journal of Haematology, July 2022

The disease course of Castleman disease patients with fatal outcomes in the ACCELERATE registry

Frontiers in Immunology, July 2022

Optimisation of anti-interleukin-6 therapy: Precision medicine through mathematical modeling

Blood Advances, August 2022

Siltuximab is associated with improved progression-free survival in idiopathic multicentric Castleman disease

Clinical Advances in Hematology & Oncology, September 2022

How we manage idiopathic multicentric Castleman disease

Leukemia, September 2022

Organ dysfunction, thrombotic events, and malignancies in patients with idiopathic multicentric Castleman disease: A population-level US health claims analysis

FACES OF CD

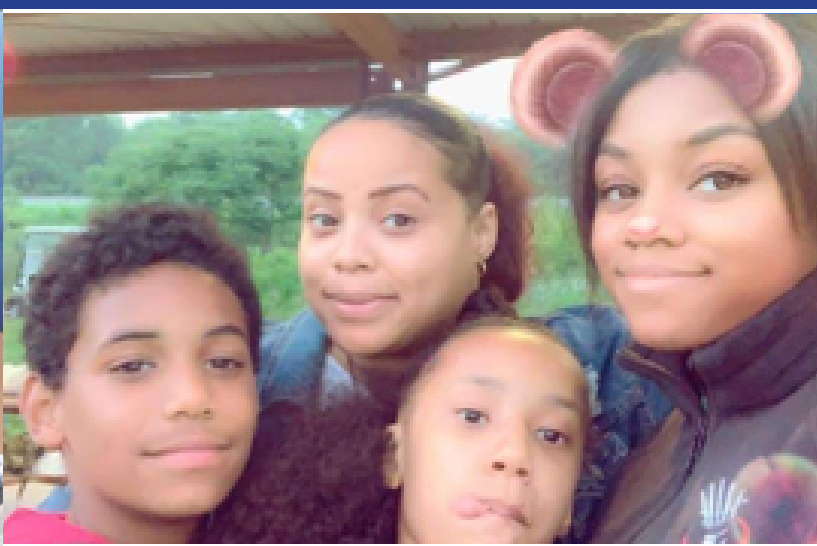


Kaila Mabus, Survivor

Kaila began her journey with the TAFRO variant of iMCD in August 2019. A few of months before her 14th birthday, she was transferred to Lurie Childrens Hospital in renal failure. She was finally given a diagnosis of iMCD 31 days later. In the last year, Kaila has spent over nine months in the hospital fighting for her life. She has endured much more than any child should - countless scans, X-rays, procedures, infusions, blood transfusions, hemodialysis treatments, chest tubes to drain her pleural effusions, pericardial drains prior to a pericardial window, endless labs, and multiple transfers to the PICU for respiratory failure and uncontrollable bleeding. She has tried various treatment plans and we are still working with her doctors to find the right protocol for her. She has taken high dose steroids, Eculizumab, iltuximab, Rituximab, Sirolimus, Tocilizumab, three rounds of Etoposide, and Cyclophosphamide, and one round of R-CHOP. She is currently taking Jakafi/Ruxolitinib as her new maintenance drug, a new CDCN discovery.

Shumekia Pettiford, Survivor

Shumekia is a 36-year-old mother of three battling iMCD. She was told in 2013 that she would not live to see 35. She has had 14 major surgeries in just three years. Having CD has been one of the biggest challenges of her life. Her body is riddled with pain every day. She says, "The tired, weary moments this disease brings are beyond me. But I push through anyway. My kids saved my life. Without them, I would have given up. But because I'm all they have, I decided that day I was diagnosed in 2013 that I was going to fight this. And I've been fighting ever since. Don't let the disease challenge you, you challenge it."



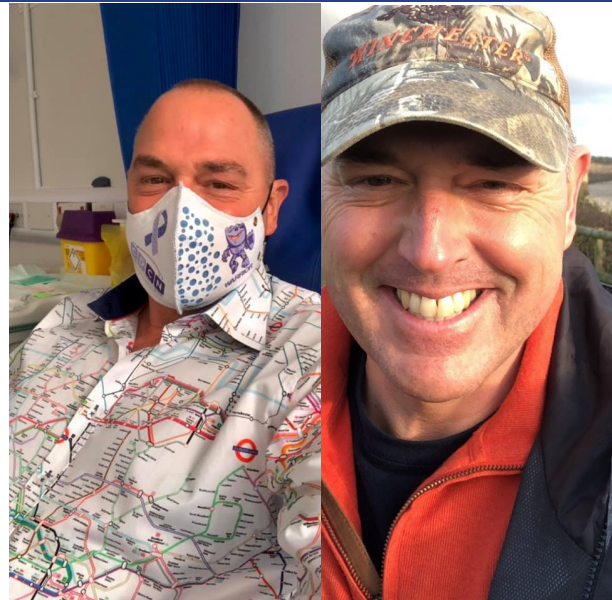


Elisa Canty, Lost Her Battle with CD

Elisa (Lisa) Miaelle Canty courageously lost her battle with Castleman disease at the age of 15. Lisa was born August 23, 2003 at Elmendorf Air Force Base, Alaska, to Diana Watson and Royce Hughes. Both of her parents were active duty army soldiers, along with her stepfather Maurice Watson. As a military child, Lisa moved from Alaska to Louisiana, and then to Fort Carson, Colorado. She had a love for horseback riding, gymnastics, and track. She was a continuous honor roll student and in 5th grade, was selected to tour the White House. She later found her passion for band and played the clarinet, percussion, and the xylophone. She also had a love for dance, skateboarding, riding her bike, riding motorcycles, and going to the gym. Lisa was diagnosed with iMCD in February of 2018, during her 9th grade year. She spent 12 weeks in the hospital battling this disease and endured respiratory failure, kidney failure, enlarged spleen, enlarged lymph nodes, liver issues, diabetes, high blood pressure, low blood pressure, pneumonia, c-diff, hallucinations, bone marrow malfunction, and high and persistent fevers. Throughout all of this, she loved being with her family and continued to fight and stay positive. She is the epitome of a fighter and she taught people how to live. She is deeply missed.

Andy Dodson, Survivor

Andy, who lives in the United Kingdom, was diagnosed with iMCD in 2017. He struggled with weight loss, debilitating pain, headaches, various vision and hearing impairments, and fatigue. He had a long diagnostic journey and an even longer battle finding the right treatment to alleviate his symptoms. In addition to the physical toll this disease took on his body, it took an emotional toll as well. He lost his job and drastically changed his lifestyle. Andy found the CDCN and attended the Patient & Loved One Summit in 2017, which left him feeling hopeful and reinvigorated his fight against CD. He has participated in many aspects of the CDCN patient journey- donating samples, joining ACCELERATE, supporting other patients, and attending events. Though he has had several relapses and failed therapies, Andy has been on siltuximab nearly 18 months and has some sort of life again!



Alice Gorman, Survivor

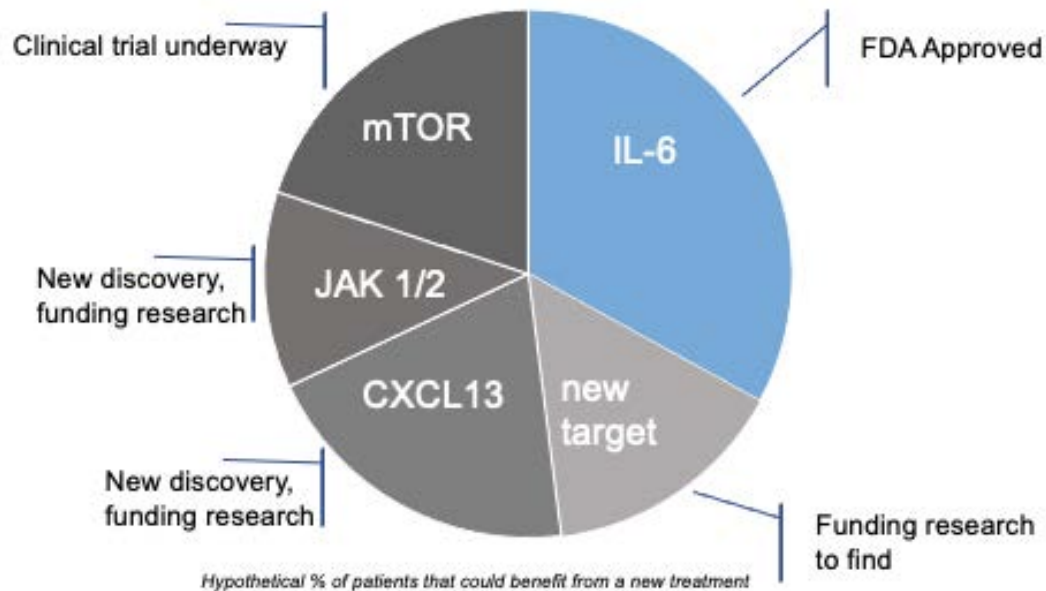
Alice was diagnosed with CD in 2015, after a year and a half of misdiagnoses. During that time, she was in and out of the hospital, underwent dialysis, had countless blood transfusions, two kidney biopsies, two lymph node biopsies, and liver problems. Her weight fluctuated by 50+ pounds in a two-week period. She finished treatments of chemotherapy and Rituximab, and so far, the results are promising. She remains optimistic, but says that the fear of recurrence is very real. Alice is dedicated to raising funds for the CDCN to help advance research and awareness so that one day, we can prevent and cure this horrible disease.



DISCOVERING NEW TREATMENTS

Not all patients respond to the only FDA-approved drug to treat iMCD.
We are on a quest to find a cure for every patient.

IMMUNE SYSTEM TARGETS TO REACH 100% OF PATIENTS WITH A VIABLE TREATMENT



The Medidata Team at the 2019 Quest for a Cure Gala in Philadelphia

RESEARCH HIGHLIGHT: Serum Proteomics

medidata

A recent study conducted broad profiling of the proteins in CD patients' blood. Our analysis generated more than 1,000 data points per patient in over 300 samples. Partnering with technology firm Medidata Solutions, we leveraged artificial intelligence and machine learning to generate important insights. Among these insights is a blood test to identify if a patient is likely to respond to Siltuximab, the only FDA-approved drug for CD. Also, a new immune system target was identified (JAK1/2) and there is already an FDA-approved drug.

The CDCN's research has saved countless patients like a 15-year-old iMCD patient named Kaila. Kaila's treating physician collaborated with the CDCN to put this new lab discovery into action and utilize an unprecedented treatment after she did not respond to other therapies.

JOIN THE FIGHT AGAINST CD



Contribute medical data to the
ACCELERATE Natural History Registry.

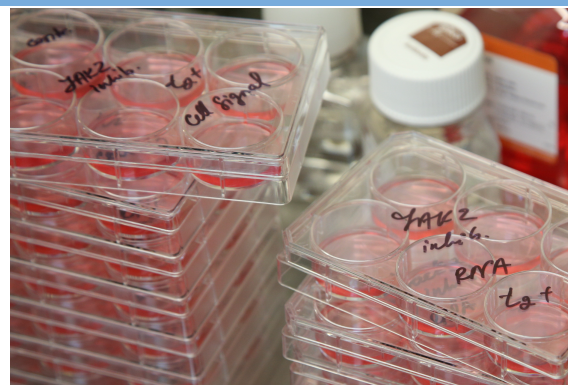


ACCELERATE is the first-ever global patient registry for CD. Created in 2016, this database combines anonymous medical data from hundreds of patients to uncover patterns, better understand CD, and improve treatment. We need more patients to enroll! Patients can enroll online in just 15 to 20 minutes. CD patients who are no longer with us can also be enrolled by surviving family members. For more information and to enroll online, visit cdcn.org/accelerate or call 215.349.5713.



Donate samples for research
through the CastleBank.

Blood and lymph node samples from patients are critical to our research. The CDCN launched a biobank to make it easy for patients to share blood samples or excess lymph node tissue samples from a clinical procedure. The CDCN handles logistics and covers costs for patients. Contact info@castlemannetwork.org or call 267.586.9977.



Support high-impact research with
monetary contributions.

Contribute to lifesaving research online at cdcn.org/donate-here or mail a check, payable to CDCN or Castleman Disease Collaborative Network, to:

Castleman Disease Collaborative Network
P.O. Box 3614
Paso Robles, CA 93447

CDCN LEADERSHIP TEAM



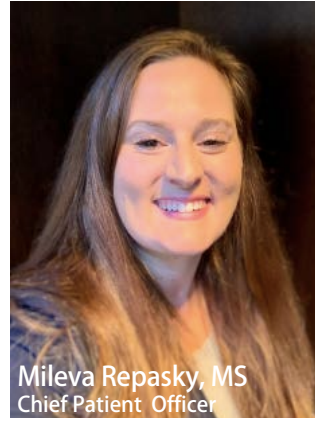
David Fajgenbaum
MD, MBA, MSc
Co-founder & President



Mary Zuccato, MBA
Executive Director



Frits van Rhee, MD, PhD
Co-founder & Cochair of
Scientific Advisory Board



Mileva Repasky, MS
Chief Patient Officer



Sheila Pierson, MS
Director of Registry
Enrollment



Michael Gonzalez, PhD
Associate Director of
Basic & Translational Research



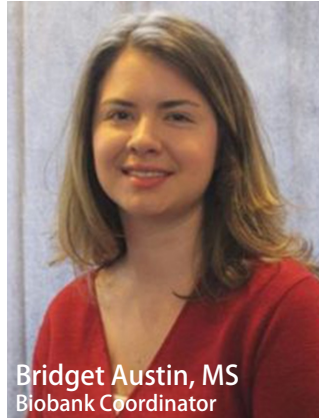
Melanie Mumau, PhD
Senior Research Investigator



Tracey Sikora, BS
Associate Director of
RAPid Clinical Trial



Amber Cohen, BA
Executive Administrator



Bridget Austin, MS
Biobank Coordinator



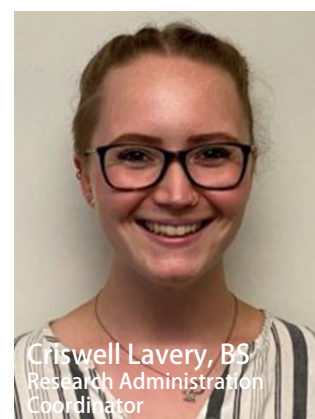
Ania Korsunski
Biomedical Leadership Fellow



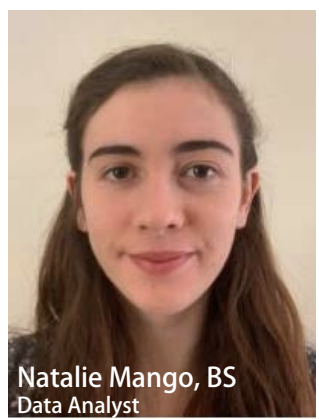
Hemi Park, MPH
Data Coordinator



Priyanka Kulkarni, MPH
Data Coordinator



Criswell Lavery, BS
Research Administration
Coordinator



Natalie Mango, BS
Data Analyst



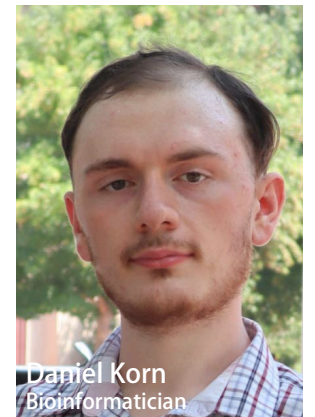
Mateo Sarmiento, BA
Data Analyst



Ira Miller
Research Specialist



Abiola Irvine, BS
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Daniel Korn
Bioinformatician



**Saishravan
Shyamsundar, MS**
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All of the amazing patients, loved ones, physicians, researchers, and donors who are part of this fight

*The CDCN pays tribute to
Glen de Vries, an extraordinary
human being and dear friend
who we lost far too soon.
We will remember him always.*

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