



IMPACT REPORT

November 2023

10 YEARS OF LIFESAVING RESEARCH

Our Mission

The Castleman Disease Collaborative Network (CDCN) is dedicated to accelerating research and treatment for Castleman disease, supporting patients on their journeys, and revolutionizing biomedical research for countless other diseases.

Our Vision

The CDCN is working to create a world where all Castleman disease patients live full lives, and patients with other conditions are benefiting from our work.



Dear CDCN Family,

When I became critically ill in 2010, the challenges seemed insurmountable. The absence of diagnostic criteria for Castleman disease (CD) meant it took several months before I received a diagnosis. Once diagnosed, there were no clinical guidelines available as to how to treat my deadly disease. And when the only known treatment for CD failed to work, it appeared I was out of options.

I dreamed of overcoming this disease and decided that I wanted to go out swinging. But never in my wildest dreams did I imagine how many punches would land. That I am here today and acknowledging the extraordinary progress made by the Castleman Disease Collaborative Network (CDCN) over the last ten years feels like a dream.

When we founded the CDCN in 2012, it was an entirely volunteer organization, beginning with just me and one of my medical school colleagues. It soon blossomed with dozens of volunteers — all of whom had full-time jobs, or were attending medical or graduate school — choosing not only to believe in our mission, but contributing thousands of hours to help it become a reality. Today, our combined team at the CDCN and the Center for Cytokine Storm Treatment and Laboratory (CSTL) at the University of Pennsylvania comprises nearly 20 full-time employees who have made our mission their life's work. The continued contributions to our team by hundreds of donors and volunteers — from our boards to our councils and more — fuel our progress every day. And our community of physicians, researchers, patients and loved ones inspire and drive forward our work.

In terms of research, our impact has been astounding. We now have established criteria to diagnose CD and a clear pathway for how to best treat it. We supported the first-ever FDA-approved treatment for CD, siltuximab, which has proven to be a gamechanger. And we have identified additional treatment options for patients who do not respond to the only treatment currently approved.

Maybe I dreamt we could have achieved one of these goals, but not all, and certainly not in only ten years. Our impact is so much greater than I ever imagined, so much more than I ever dreamed. And it extends far beyond CD.

We have inspired significant funding to replicate and scale our research model to benefit more than 50 other rare diseases. And we have co-created the nonprofit organization Every Cure, aimed at unlocking the hidden potential of the 3,000 drugs approved by the FDA to treat many of the 10,000 rare diseases without approved therapies.

Today, approximately half of all patients with CD are responding to the treatment options identified thus far, and there is every indication we will be able to live full lives. But nearly half of our patient community is still waiting for these solutions. Our work is far from done.

We will continue our relentless pursuit for a cure until every child and adult diagnosed with CD can live a long, healthy, wonderful life. Thank you for joining us on this mission.

Sincerely,

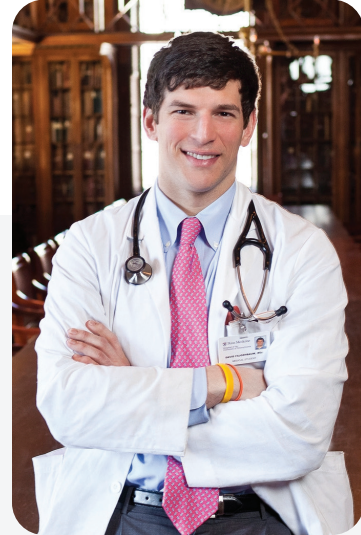


David Fajgenbaum, MD, MBA, MSc, FCPP
Cofounder and President, Castleman Disease Collaborative Network (CDCN)
Founding Director, Center for Cytokine Storm Treatment and Laboratory (CSTL)
Associate Professor of Medicine, University of Pennsylvania

The Origin of the CDCN



David Fajgenbaum, MD, MBA, MSc, FCPP



It was 2012, and David Fajgenbaum was lying in the hospital surrounded by his family and his girlfriend Caitlin. His vital organs were shutting down and he was in unbearable pain. It was his fourth deadly relapse of Castleman disease. His physician, Frits van Rhee, MD, had just explained, “David, we’ve tried everything. The only drug in development failed to work. There is nothing more we can do.”

A year earlier, David had his last rites read to him. And he had already nearly died three times. But this was by far the lowest point, because his doctor was saying there was no more hope. No more treatments. That he would not be able to chase cures for cancer as a physician like he promised his mom before she passed. He would not be able to marry Caitlin and have a family one day like he dreamed of. And he would not be able to measure his life in years or decades. It would now be weeks or maybe months.

After a few minutes of tears and silence, David turned to his dad, sisters and Caitlin, and told them he would dedicate the rest of his life, however long that may be, to trying to find an effective treatment for himself and patients like him. He would need to create hope through taking action. It was in that moment Dr. van Rhee agreed to join forces with David and cofound the Castleman Disease Collaborative Network (CDCN).

In a last-ditch effort to save David’s life, Dr. van Rhee prescribed a combination of seven chemotherapies. Somehow, David survived and set out on a mission together with Dr. van Rhee — a mission to accelerate research and treatment for Castleman disease, with the goal of improving survival for every single child and adult diagnosed. And they would not stop until every patient with CD could live a full life after diagnosis.

The Castleman Disease Collaborative Network (CDCN) is a global nonprofit organization cofounded in 2012 by David Fajgenbaum, MD, MBA, MSc, FCPP, and Frits van Rhee, MD, PhD, in response to the urgent need to advance research for this rare and potentially deadly disease, and improve patient care and survival.



Frits van Rhee, MD, PhD

Understanding Castleman Disease

About CD

Castleman disease (CD) describes a **group of rare inflammatory disorders** that present with a broad range of symptoms similar to autoimmune diseases and cancers, and can lead to life-threatening multiple organ failure.

Subtypes of CD

There are **four main subtypes** of Castleman disease. Each subtype involves different symptoms, causes and treatment approaches.

- 1 Unicentric Castleman disease (UCD)
- 2 POEMS-associated multicentric Castleman disease (POEMS-MCD)
- 3 HHV-8-associated multicentric Castleman disease (HHV-8+MCD)
- 4 HHV-8-negative/idiopathic multicentric Castleman disease (iMCD)

As Deadly as Cancer

An estimated **25 to 35%** of patients with idiopathic multicentric Castleman disease (iMCD) — the deadliest form of CD — will die within **five years** of their diagnosis.

Many receive an inaccurate diagnosis of lymphoma before a correct diagnosis is made, and are initially relieved they have iMCD until they learn it is actually **worse than cancer**.



Prevalence

Each year, approximately **5,000** children and adults are diagnosed with CD in the US and many more are diagnosed around the world. Because CD mimics several other diseases, individuals often suffer for months and sometimes even years before they receive an accurate diagnosis.



Treatment

With the support of the Castleman Disease Collaborative Network, there is now **one treatment approved** by the FDA, which has proven effective for one-third of patients. The CDCN has also discovered the first new treatment option for CD in 25 years, and identified and advanced research for 12 more promising treatments.

While the CDCN has made remarkable progress, nearly **50% of children and adults** with CD do not respond to the therapies uncovered to date. The need to identify additional lifesaving treatments remains urgent.



The Faces of Castleman Disease

Joseph Coates | Kent, Washington

Joseph Coates' journey with CD began in April 2023 when he awoke with abdominal pain, bloating and fatigue. His local urgent care center sent him straight to the hospital emergency room. Tests revealed he had fluid in his belly, and his lymph nodes and organs were enlarged. He was initially diagnosed with leukemia. Within three weeks, Joe lost 20 pounds and significant muscle mass. His body was deteriorating. It would take another four months before he was properly diagnosed with POEMS-associated multicentric Castleman disease (POEMS-MCD).

“

I am still in the beginning stages of my disease, but I'm very hopeful. And I'm so thankful to have met my CDCN family.



In researching his disease, Joe came upon the story of Dr. David Fajgenbaum and felt an instant connection. Finally, he saw there was a way out. He picked up the phone and called the CDCN, and within a week, Joe and his girlfriend were on their way to Philadelphia for the CDCN Patient and Loved One Summit, where his journey would begin to move in a more positive direction.



Aubrey Settles | Delta, Pennsylvania

Aubrey Settles was only six years old when a lymph node excision in May 2023 led to a CD diagnosis. She had already endured so much, from a chronic sore throat that led to the removal of her tonsils and adenoids, to bouts of extreme exhaustion that caused her to skip meals so she could sleep. The pain was everywhere, and Aubrey's mother was taking her to the pediatrician several times a week. Finally, a biopsy ordered by an ENT revealed Castleman disease.

“

The CDCN means we are not alone. They've provided me and my family with the support and information needed to navigate this frustrating journey of the unknown. They've led us in the right direction.

— Kerry Moore, Aubrey's Mother

Aubrey is now seven, and her medical team is still looking to identify a treatment that will help. Steroids relieve some of the swelling and other symptoms, but there are flare-ups. Aubrey's resilience continues to amaze her parents and siblings every day. She is a smart, funny, kind, beautiful young lady who loves school, animals and playing outdoors with friends. And she is a fighter.

Bethany Thomure | Farmington, Missouri

In her young life, Bethany Thomure had already experienced a complicated medical odyssey — rheumatoid arthritis, lupus, cervical cancer, kidney failure and a hysterectomy. It was in February 2023, after first receiving a diagnosis of lymphoma, that 33-year-old Bethany was diagnosed with Castleman disease. Her subtype was just recently determined as idiopathic multicentric Castleman disease (iMCD).

She found the CDCN through online research and quickly became engaged in the Facebook support group. And in August 2023, she embarked on her first solo trip ever to attend the CDCN Patient and Loved One Summit in Philadelphia. The team helped her schedule an appointment with CDCN cofounder and CD expert Frits van Rhee, MD, PhD, in Arkansas, and Bethany knows she will soon be on the right track to treatment. Now age 34, the self-proclaimed “happy dog mom” continues her career in human resources, runs two book clubs, and loves plants, Halloween and her husband.

“

This disease has changed me more than any other, and the way the CDCN community has embraced me means everything. It's still scary, but to know there are treatment options, and to see so many other CD patients doing well, gives me hope.



Eva Lally | Galway, Ireland

Eva Lally was 52 years old when she began experiencing abdominal pain in 2020. After two failed colonoscopies, she was referred

to a colorectal surgeon, who ordered a colonography. The imaging revealed enlarged lymph nodes and was quickly followed by a laparotomy in December 2021. Eva's pathology report indicated idiopathic multicentric Castleman disease (iMCD), but because the diagnosis is rare, it took several weeks before the results were confirmed. Her symptoms soon worsened, including night sweats, severe itching, joint pain and extreme fatigue.

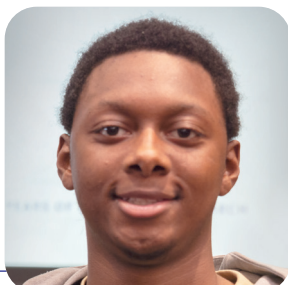
Since March 2022, Eva has been undergoing treatment with siltuximab. Her health continues to improve and she is confident her iMCD will soon be under control. She plans to return to her busy career in medical device manufacturing after a two-year absence. And she says she has made a conscious decision to savor life — attending Bruce Springsteen concerts, creating unique flags, and meeting friends and colleagues for coffee and a good laugh.



“

The CDCN came into my life like a torch in the darkness. I'm so impressed with their research and their genuine connection to patients. I have found my tribe. And I'm eternally grateful.

Avion Dent | Blaine, Minnesota



“

Avion's doctors worked very closely with the specialists at the CDCN throughout his diagnosis and to develop his treatment plan. The CDCN saved my son's life.

– Erika Reggs, Avion's Mother

Avion Dent was enjoying high school as a superstar athlete in football, basketball and track. He was 15 years old when he began experiencing pain in his legs and soon after, in his stomach. After numerous failed visits to the ER, Avion became so severely ill he was finally admitted to the regional children's hospital in July 2022. He would remain there until December, enduring two strokes, a coma and a code red. It was on his 16th birthday that the medical team diagnosed him with idiopathic multicentric Castleman disease (iMCD).

After a series of chemotherapy treatments, Avion is now on siltuximab. He tires quickly and sports no longer come easily, but he continues to build back his strength. Now age 17, Avion enjoys video games and hanging out with friends, and serves as a volunteer coach with several local youth teams. He has donated blood and tissue samples for research, and in 2023, attended his first CDCN Patient and Loved One Summit with his mom.

Emmanuel Morales | Ambler, Pennsylvania

Emmanuel “Manny” Morales was first admitted to the hospital on March 29, 2022, with abdominal pain, chills and nausea. Initial tests revealed a large mass in his chest and hemorrhaging in his adrenal glands, but a diagnosis remained elusive. With steroids controlling his pain, Manny was released from the hospital while testing continued. Just days later, he was readmitted with multiple organ failure and soon transferred to one of the city's leading academic medical centers.

There was extensive testing and unsuccessful dialysis for his failing kidneys. He was placed on a ventilator. On April 26, a lymph node biopsy, delayed multiple times due to Manny's severely low blood pressure, was finally performed bedside. It revealed Castleman disease. His girlfriend's sister googled CD and immediately emailed Dr. David Fajgenbaum, who responded in 11 minutes. But it would all come too late. Manny passed away on May 1, 2022, at the age of 36, surrounded by family and friends.



“

Manny was the nicest person you could ever meet. He was passionate about Philadelphia sports. He was a big kid at heart. He loved reading and learning. And he was so giving. Everyone at the CDCN immediately opened their arms to our families. They've been wonderful.

– Megan Harakal, Manny's Girlfriend

Our Unique Model

The CDCN's highly unique model includes the creation of a global network to collaborate across research initiatives, the direct engagement of patients in that research, the concept of drug repurposing to find solutions rapidly and efficiently, and a working environment where research and patient care occur side by side.

The Collaborative Network Approach

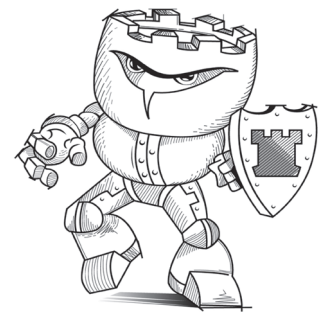
The CDCN developed a groundbreaking, patient-centered research model known as the Collaborative Network Approach. This approach involves:

- Crowdsourcing the most important research questions from across the patient, loved one, physician and researcher communities
- Identifying and prioritizing the options yielding the highest impact
- Recruiting the most qualified researchers in the world to conduct those studies

We have connected an ever-expanding global network comprising over 2,000 patients and loved ones, and more than 900 physicians and researchers in 82 countries, who work collaboratively to advance research and improve patient care.

Castleman Disease Warriors

Patients with Castleman disease — referred to by the CDCN as **Castleman Warriors** — play a critical role in finding answers, as the organization's research is fueled by their ongoing donations of blood and tissue samples for the CastleBank biobank, clinical data for the ACCELERATE patient registry, and vital input in establishing research priorities.



Drug Repurposing

Rather than spend decades of time and billions of dollars developing novel therapies, the CDCN's pioneering methodology focuses on identifying treatments already hiding in plain sight — existing therapies approved for other conditions that can be expeditiously repurposed to treat Castleman disease and other diseases.

The CSTL

In addition to his role as cofounder and president of the CDCN, Dr. Fajgenbaum is the founding director of the Center for Cytokine Storm Treatment and Laboratory (CSTL) at the University of Pennsylvania. It is the first center integrating top-notch clinical care, clinical trial opportunities, and basic, translational and clinical research for CD in the US. The CSTL is fully integrated with the CDCN to create



a uniquely collaborative environment where scientific research and world-class patient care occur hand in hand, and optimal treatment approaches are directly informed by the patient experience.

The CDCN focuses on facilitating collaboration among the entire global Castleman disease community, mobilizing every resource available, strategically investing in research that will yield the highest impact, and supporting patients and their loved ones in every way, so that no one is facing Castleman disease alone.

The CDCN Community

The Castleman Disease Collaborative Network hosts or participates in numerous initiatives throughout the year to build awareness for Castleman disease, raise funds for critical research, and provide trusted information and support to patients and loved ones.

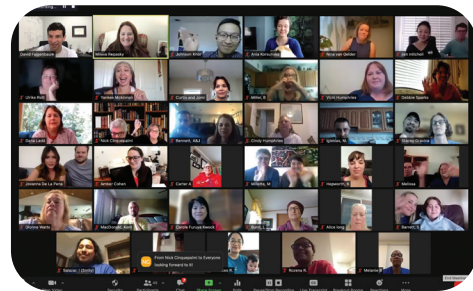


Patient and Loved One Summit

Each year, about one hundred patients and loved ones travel from around the world to attend our annual Patient and Loved One Summit. This two-day event features information sessions, scientific panels, Q&As with the experts, support groups and more. The Summit is live streamed for those who cannot attend and recordings are available following the event.

Community Gatherings

The CDCN hosts hour-long Zoom meetings for CD patients and loved ones on an ongoing basis. Led by our experts and various guest presenters, this forum is utilized to present new research and treatment updates, respond to questions submitted by the community, and establish a welcoming space where patients and loved ones can connect with one another.



Quest for a Cure Gala

The Quest for a Cure gala, held annually in Philadelphia, is the CDCN's premier fundraising event. Several hundred guests attend the gala each year to learn about the organization's latest breakthroughs in research, and to meet CD patients and their families.

World Castleman Disease Day

World Castleman Disease Day is recognized each year on July 23 by the entire CD community — patients, loved ones, physicians and researchers. It marks a time when everyone unites in a concerted effort to build greater awareness for CD, to support patients who are living with this disease, and to remember and honor those we have lost.



Million Dollar Bike Ride

The CDCN comes together each year to form our own team for the Million Dollar Bike Ride (MDBR). Hosted by the Penn Medicine Orphan Disease Center, the MDBR raises much-needed funding for rare disease research. In the nine years since its inception, the MDBR has raised more than \$15 million for research across dozens of rare diseases.

10th Anniversary Celebration

In September 2023, the CDCN celebrated ten years of lifesaving research with a special gathering at the 6abc Action News Studio in Philadelphia. The event featured a captivating conversation between Dr. Fajgenbaum and 17-year-old CD patient Kaila Mabus, and honored the exceptional contributions of some of the CDCN's most dedicated supporters.



Our Impact on Castleman Disease

The CDCN has made more progress toward understanding and effectively treating Castleman disease in the last ten years than in the previous 50 years combined. There is now hope for patients with CD and their loved ones where there was no hope before.

Since our inception in 2012, the CDCN:

- Established the **first-ever diagnostic criteria** for CD
- Developed the **first-ever treatment guidelines** for CD
- Secured an ICD-10 code — a **unique medical diagnosis code** that classifies Castleman disease
- Supported FDA approval of siltuximab, the **first-ever treatment approved** for iMCD
- Discovered sirolimus, the **first new treatment option** for CD in 25 years
- Identified and advanced research on **12 more promising treatments** and counting, including ruxolitinib, rituximab, adalimumab, velcade-dexamethasone-thalidomide, anifrolumab, emapalumab, thalidomide-cyclophosphamide-prednisone, eculizumab, trametinib, sapanisertib and anti-CXCL13/CXCR5 therapies
- **Connected and supported** hundreds of doctors and thousands of patients around the world
- **Saved thousands of lives**

The CDCN represents a lifeline for thousands of patients around the world, approximately half of whom are responding to treatments the CDCN has identified or supported the advancement of.

Our Impact Beyond CD



Understanding the Immune System

The brilliant and passionate team of researchers at the CDCN and the CSTL is dedicated to unlocking the mysteries of the immune system to find a cure for Castleman disease. Through our work, we also aim to discover key learnings that will support treatment identification for numerous other autoimmune diseases. We demonstrate this commitment by rapidly sharing our research findings with the broader scientific community through articles published in the leading medical journals. In sharing our discoveries, the progress we have made is generating tremendous strides in medical science overall.



Battling the COVID-19 Pandemic

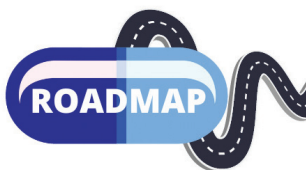
When the COVID-19 pandemic gave rise to a global crisis, the CDCN contributed our valuable drug repurposing expertise to launch the CORONA Project — the largest international effort to systematically track and evaluate the more than 600 treatments considered for COVID-19. This data set served as the primary source for the largest COVID-19 clinical trial in the US. The two drugs that saved the most lives during the pandemic were dexamethasone and tocilizumab, which are both often utilized to treat Castleman disease. In fact, tocilizumab was created by CDCN Scientific Advisory Board member Kazu Yoshizaki.



RARE AS ONE PROJECT

Inspiring a New Approach to Rare Disease Research

The novel strategy instituted by the CDCN to engage physicians, researchers and patients in research now serves as the exemplar for rare disease research. The Chan Zuckerberg Initiative (CZI) identified the CDCN's approach as the most high-impact and promising in the entire medical field, and to date, has invested over \$30 million to replicate and scale this model for more than 50 other rare diseases through a program called the Rare As One Project.



Launching the Roadmap Project

The unique approach instituted by the CDCN to focus on repurposing existing medications to treat CD now serves as the exemplar for rare disease drug repurposing. CZI provided funding for the CDCN to launch the ROADMAP project — an acronym for "Repurposing Of All Drugs, Mapping All Paths." In 2023, the CDCN launched the ROADMAP interactive tool, a comprehensive resource providing guidance and support to rare disease organizations seeking to pursue drug repurposing, based on real-world experiences.



Unlocking More Repurposed Drugs Through Every Cure

Upon reading the memoir *Chasing My Cure: A Doctor's Race to Turn Hope into Action* in 2021, former President Bill Clinton called the author — Dr. Fajgenbaum — to express his excitement about the CDCN's work. President Clinton asked Dr. Fajgenbaum about his vision for the future and he shared his vision for the CDCN to expand its innovative approach to drug repurposing to benefit other diseases. One year later, with the support of the Clinton Global Initiative and additional partners, Dr. Fajgenbaum cofounded the nonprofit organization Every Cure, with the aim of unlocking the full potential of existing medications already sitting on the pharmacy shelf to treat every disease and every patient possible. And by leveraging the power of artificial intelligence (AI), both the CDCN and Every Cure will have a revolutionary impact on identifying effective treatments for CD and thousands of other diseases.

Milestones

1954

Castleman disease is first described in a patient by Benjamin Castleman, MD.

Limited progress would be made in classification, prognosis or treatment for more than 50 years.

2012

The Castleman Disease Collaborative Network is established.

David Fajgenbaum, MD, MBA, MSc, FCPP, dedicates whatever time he has left to find a cure for his disease and for the thousands of other patients with CD. He is joined by his physician, Frits van Rhee, MD, PhD, in founding a global nonprofit organization to advance research into CD, and improve patient care and survival.

2017

The National Institutes of Health (NIH) awards its first-ever RO1 grant for iMCD research.

This is a significant triumph, as the R01 is one of the most competitive grants offered by the NIH. It will support a major clinical trial for sirolimus, the promising treatment option identified by Dr. Fajgenbaum — and the one that brought him into remission.

2016

The CDCN launches ACCELERATE.

It is the first-ever global natural history registry for patients with CD.

2010

Third-year medical student David Fajgenbaum is diagnosed with idiopathic multicentric Castleman disease (iMCD)—the deadliest form of CD.

For the next two years, he would spend months in the intensive care unit, enduring unproven treatments and multiple relapses, and nearly dying five times. His journey made him acutely aware that while the majority of people assume there are brilliant scientists around the world studying every disease, the reality is that for many diseases — particularly rare diseases — there is no research underway and no effective treatments identified.

2014

The CDCN's International Research Agenda is launched.

It is the result of a highly collaborative effort by medical experts around the world.

2018

CDCN researchers identify which iMCD patients are most likely to respond to siltuximab.

With IL-6 identified by CDCN Scientific Advisory Board member Kazu Yoshizaki as playing a key role in Castleman disease, this study predicts which patients will respond to siltuximab as a first-line treatment for iMCD.

2014

With the CDCN's support, siltuximab is approved by the FDA.

It is the first-ever approved treatment for idiopathic multicentric Castleman disease (iMCD) and effective in one-third of iMCD patients.

2017

The CDCN publishes the first-ever diagnostic criteria for CD.

Physicians now have more information to help identify this disease in patients. Still, it remains an inherent challenge for the medical community to be fully aware of the estimated 10,000 known rare diseases.

2013

The CDCN assembles the Scientific Advisory Board.

This global network of physicians and scientists agrees to prioritize Castleman disease and together, set the overall direction for research.

2018

The CDCN releases the first-ever treatment guidelines for iMCD.

These guidelines are based on data from more than 300 patients and represent an enormous breakthrough for patient care and survival.

2019

Our researchers discover the mTOR pathway is a novel therapeutic target for CD.

The results are published in the *Journal of Clinical Investigation*.

2020

Tocilizumab is identified to be effective in treating patients with the most severe cases of COVID-19.

This medication was developed in Japan in the 1990s by CDCN Scientific Advisory Board member Kazu Yoshizaki to treat Castleman disease.

2020

***Chasing My Cure: A Doctor's Race to Turn Hope into Action* becomes a national bestseller.**

Dr. Fajgenbaum's powerful memoir chronicles his journey with the deadliest form of CD and his quest to find lifesaving treatment.

2021

The CDCN publishes major outcomes from the SPEED2 study. It is just one of many studies conducted by the CDCN to hone in on immune targets.

2021

The CDCN discovers that ruxolitinib may be effective in treating CD.

The first patients treated with this medication achieve remission, opening the door for a clinical trial.

2022

The CDCN marks a decade of lifesaving research. While our accomplishments offer much to be proud of, our team never loses sight of the significant work that remains.

2023

The NIH awards a five-year R01 renewal grant to our lab at Penn. We are likely one of the first labs ever to receive R01s on our first three submissions and almost certainly the youngest principal investigator to receive three of these research grants.

2022

Researchers at Penn, the CDCN and partner Medidata uncover evidence that adalimumab may effectively treat iMCD. This represents a significant breakthrough.

2022

The FDA awards a four-year R01 grant to Dr. Fajgenbaum's lab at Penn for the ACCELERATE Registry.

The CDCN's groundbreaking, patient-centered research model — the Collaborative Network Approach — and our focus on repurposing existing treatments approved for other conditions in the fight against Castleman disease, has led to unprecedented impact and saved thousands of lives around the world. Still, only half of patients with CD are responding to the treatments identified to date.

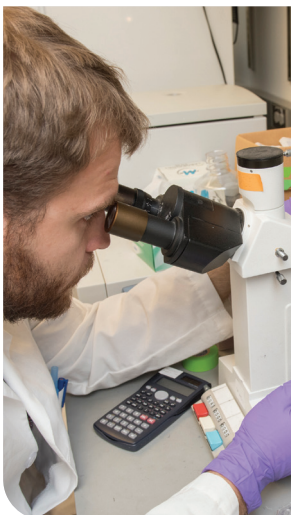
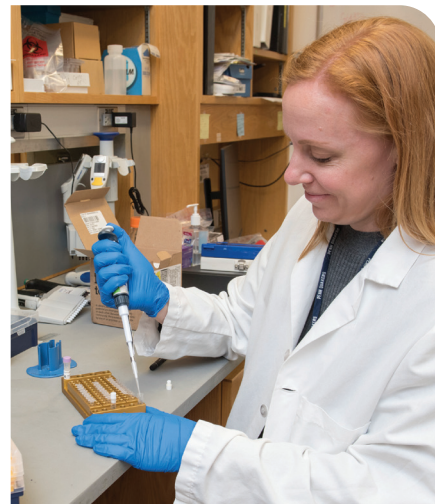
Our work is far from done.

An Eye Toward the Future

While the CDCN has made remarkable progress in our pursuit of a cure for Castleman disease, nearly 50% of children and adults with CD do not respond to the therapies uncovered to date. While the CDCN has identified 12 potential new targets and treatments, the need to evaluate these promising opportunities and identify additional lifesaving treatments remains urgent.

As we chart our path for the future, our priorities are many.

- We will focus on developing blood and lymph node tests to definitively diagnose CD, enabling patients to receive treatment faster.
- We will advance research into five promising drug repurposing options, moving forward with intensive investigative studies and clinical trials.
- We will seek and acquire the funding needed to conduct the multiple research studies currently waiting in our pipeline.
- We will continue to identify new treatment targets for CD patients who are not responding to current options or for whom options do not yet exist.
- We will persist in our relentless pursuit for a cure until every patient diagnosed with CD has a treatment that works.



Join the Fight

For Patients and Loved Ones



Contribute Medical Data to the ACCELERATE Natural History Registry

ACCELERATE is the first-ever global patient registry for Castleman disease. This invaluable database combines anonymous medical data contributed by hundreds of CD patients to help researchers identify patterns, build our understanding of CD and improve treatment options. Patients are encouraged to enroll in ACCELERATE at any stage of diagnosis and treatment, and can also be enrolled by surviving family members. For more information or to enroll, visit cdcn.org/accelerate or call 215.614.0209.



Donate Samples for Research through CastleBank

The CastleBank is a biobank for the collection and study of blood and lymph node tissue samples donated by CD patients. The continued donation of these samples is critical to conducting our research. The CDCN has made it very easy for patients to share blood samples on an ongoing basis, and to share excess lymph node tissue samples from clinical procedures. Our organization will handle all logistics and cover all costs. Contact us at info@castlemannetwork.org or 267.586.9977 to learn more.

For Everyone



Support High-Impact Research with Financial Contributions

As a nonprofit organization, the CDCN relies on financial contributions from individual donors and foundations to fund promising research studies and facilitate meaningful patient support initiatives. We hope you will consider supporting our lifesaving work. Contributions can be made online at cdcn.org/donate-here or by check, payable to either CDCN or Castleman Disease Collaborative Network, and mailed to Castleman Disease Collaborative Network, P.O. Box 3614, Paso Robles, CA 93447. If you wish to speak with us regarding a gift, contact us at info@castlemannetwork.org or 610.304.0696.

With Gratitude

The Castleman Disease Collaborative Network wishes to recognize many of the extraordinary donors who have enabled our growth and accomplishments over the past ten years.

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Though we are so thankful for every single gift and wish to acknowledge every contribution, it is possible that a gift was omitted from the list above. Please accept our apologies if this is the case and know how appreciative we are of your contributions to this critical work.

Why We Support the CDCN



Marjorie Raines
Coral Gables, Florida

It was Marjorie Raines' son David Chillura who first asked if she would consider supporting the CDCN. David knew CDCN cofounder David Fajgenbaum as a former teammate on the Georgetown football team. Marjorie reached out to Dr. Fajgenbaum to learn more and knew immediately this would be a cause she was going to embrace for the long-term. Over the years, she has visited David's lab at Penn, accompanied him on hospital rounds, and joined

“The CDCN has keyed in on an innovative, economical, highly scientific approach to curing Castleman disease, and it translates universally to other diseases. This organization has given us a window to the world through its vision. There is a unity of purpose, and I'm so proud to offer my support.”

the CDCN Advisory Council. Marjorie recognized the CDCN's potential for impact beyond CD and encouraged the organization to scale its approach to other immunological diseases and rare diseases, leading to lifesaving partnerships with the Chan Zuckerberg Initiative and Every Cure. Her continued support over the years has funded numerous impactful studies, including those that identified the first-ever gene mutation considered as a possible cause of CD and the first novel CD treatment in 25 years.



Paul Robbins
Jacksonville, Florida

“Everyone at the CDCN is so driven and passionate about finding a cure. And they're making tremendous strides. I'm not a scientist or physician, but I can help by providing financial support. How else will this disease ever be cured?”

Paul Robbins' plan for retirement was to purchase a motorhome and tour the US with his wife. He was able to take one trip before falling ill in December 2019. After months of spinal taps, biopsies and excisions, he received a diagnosis of idiopathic multicentric Castleman disease (iMCD). Over the next few years, Paul endured a series of treatments that led to temporary remissions, but the side effects were severe and relapse always followed. At the CDCN's urging, Paul traveled to Philadelphia to meet with the experts at Penn and followed their recommendation for treatment with siltuximab. He experienced an extended remission before relapsing and is currently recovering at home in Florida. Throughout these ups and downs, Paul has donated blood and tissue samples for research. And he continues to support the CDCN financially with extraordinary generosity.



Elizabeth Crowley
Concord, Massachusetts

Liz Crowley fell completely in love with her nephew Jasper Avina the moment he was born. When he became critically ill at just 11 years old, the entire family was distraught. It took months before Jasper would be diagnosed with Castleman disease. There were multiple hospitalizations, and a life flight helicopter from Jasper's home in New Mexico to a children's hospital in Colorado. When Jasper's mom Megan discovered the CDCN through her research, she knew they had found hope. Jasper's blood and tissue samples were sent in advance to the CDCN lab, and Liz accompanied Megan and Jasper

“I am first and foremost Jasper's aunt. Finding a cure is what I hope for. But supporting the CDCN is much bigger than that. It's the “CN” in the name that matters. With a collaborative network, it's about how many can contribute and how many can benefit. I want to be a part of that.”

to Philadelphia to meet with the medical team to get answers they desperately needed. Now age 14, Jasper is in full remission. He loves swimming, guitar, animals, dirt bikes and spending time with friends. Like Megan, Liz thinks about the unknown future of CD every day. But she knows there is a way forward and it is supporting the CDCN.

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The CDCN offers much-needed hope to individuals with Castleman disease and their loved ones, skillfully turning hope into action and promising research into permanent cures.



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