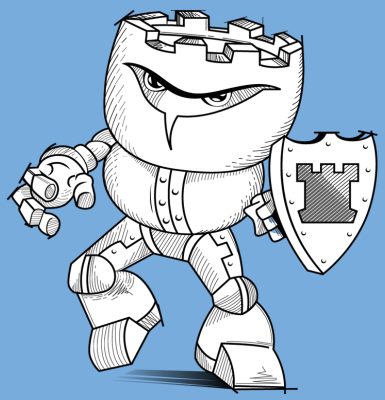


CASTLEMAN DISEASE COLLABORATIVE NETWORK

2019 - 2020

COMMUNITY UPDATE

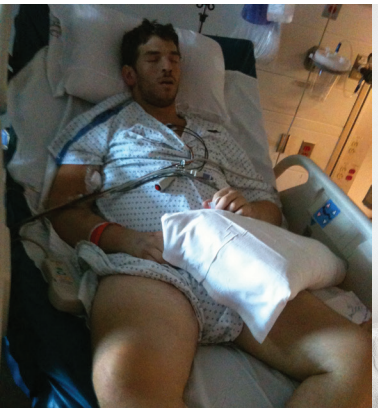
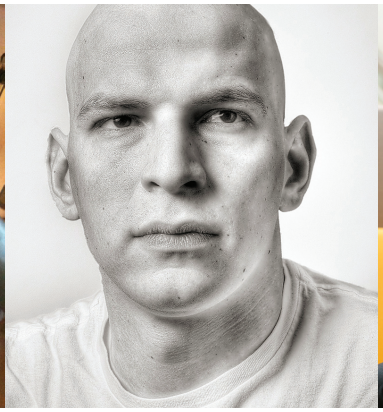
CDCN

CASTLEMAN DISEASE COLLABORATIVE NETWORK

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, raising funds, strategically investing in high-impact research, and supporting patients and their loved ones.

DEAR CASTLEMAN DISEASE FAMILY

It is amazing how far we have come together.

When Dr. Frits van Rhee and I started the CDCN in 2012, Castleman disease (CD) was very poorly understood by the medical community. There were no diagnostic criteria, treatment guidelines, or FDA-approved treatments. And there was no research infrastructure to change things: no cell lines, registries or biobanks, no federal funding, and no collaborative research network to advance understanding and treatment.

With support from incredible patients, loved ones, physicians, researchers, volunteers, and donors, we have taken back momentum in the war against CD. We established the first-ever diagnostic criteria and treatment guidelines for the most severe subtype of CD (idiopathic multicentric CD, iMCD). We launched a patient registry (ACCELERATE) and biobank (CastleBank) that allow patients to contribute data and samples and 15 additional high-impact studies that are using these data and samples. Siltuximab became the first-ever FDA-approved treatment for iMCD in 2014, and CDCN research recently uncovered ways to identify which patients are likely to improve on it or not. Now, the first clinical trial for siltuximab non-responders has opened at the University of Pennsylvania and the University of Arkansas for Medical Sciences. Based on CDCN research, my lab recently received the first-ever federal grant to study iMCD. We continue to support and connect thousands of patients and loved ones affected by CD through events and online forums. The CDCN's innovative "Collaborative Network Approach" and our groundbreaking progress inspired the Chan Zuckerberg Initiative to partner with the CDCN to spread our approach to other rare diseases.

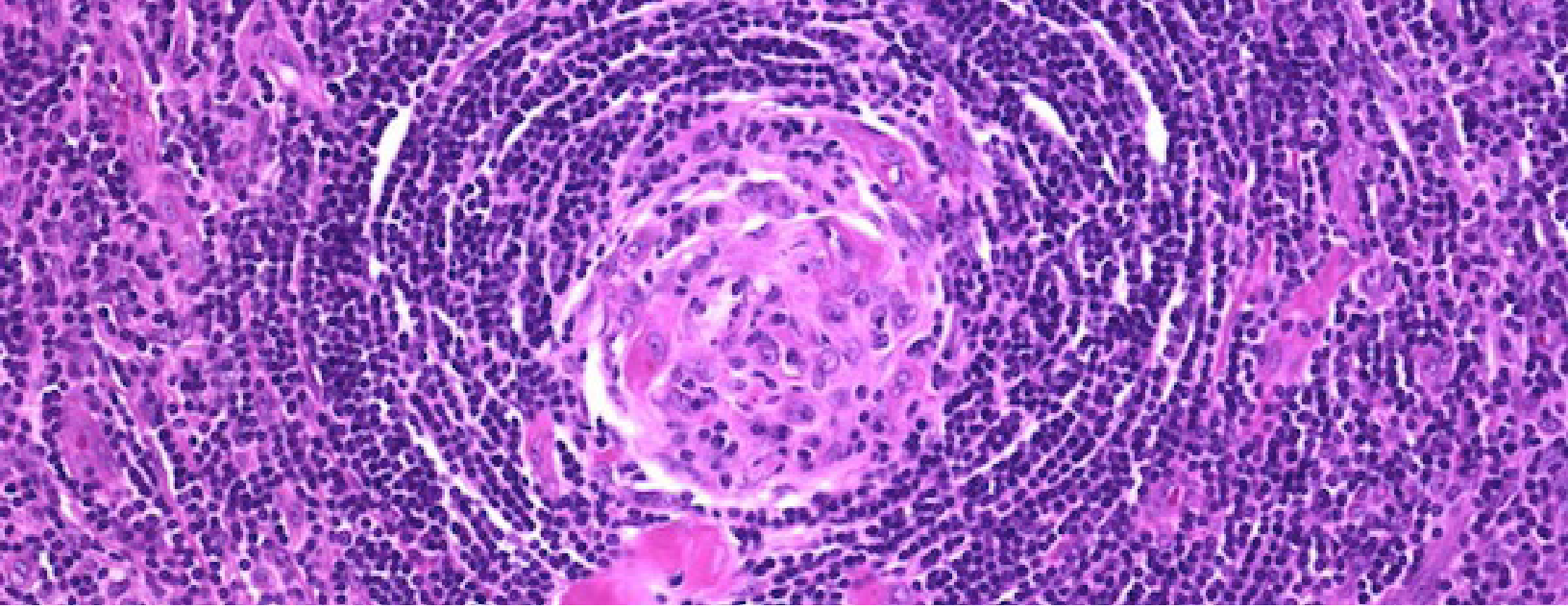
Despite our progress, much work still remains. Better treatments and cures are urgently needed. And we can't do it alone. We need everyone to join together. Patients can fight back by contributing their medical data to the ACCELERATE registry, giving blood samples for research, and supporting one another. And anyone can donate funding to our life-saving research.

The fight against CD is personal to me—I am also a patient. I was diagnosed with iMCD in my third year of medical school. I spent 5 months hospitalized in critical condition and had my last rites administered to me when my doctors thought I wouldn't survive. While I've had multiple life-threatening relapses, with the global CDCN community and infrastructure, I'm more confident than ever that our work will extend my life and the lives of thousands of others.

Please join us as we spearhead a roadmap to cure CD and other rare diseases and learn more about how your investment in this cause will help us turn promising research into permanent cures.

Sincerely,

David Fajgenbaum, MD, MBA, MSc, FCPP
Co-Founder & Executive Director, CDCN
Assistant Professor of Medicine, University of Pennsylvania



CASTLEMAN DISEASE

A Complex Puzzle We Can All Help Solve

Every year, thousands of patients suffer from one of the debilitating forms of Castleman disease (CD). Our focus is on bringing together all those who are working to save and extend the lives of these patients. The CDCN supports cutting-edge research that is advancing the treatment of this disease on a global scale. In tandem with this vital research comes the support for those who suffer from CD, as well as their families and loved ones who are also a part of this journey.

CASTLEMAN DISEASE BEFORE THE CDCN

In 2012, CDCN co-founder Dr. Fajgenbaum returned to medical school after a year of medical leave spent battling CD as a patient. His first step was to grasp the current state of CD research. He observed major gaps in our knowledge of the disease and uncovered issues that were slowing progress, including:

Challenges Within Castleman Disease Research

- Lack of collaboration between physicians and researchers.
- Inaccurate information.
- Absence of consensus criteria for diagnosing CD.
- Faulty disease model and general misunderstanding of disease.
- Precious patient samples being stored away in freezers for years with no research.

Next, Dr. Fajgenbaum studied the rare disease research field alongside Dr. Arthur Rubenstein at the University of Pennsylvania and found systemic issues within the larger biomedical research community that were also slowing progress for CD research.

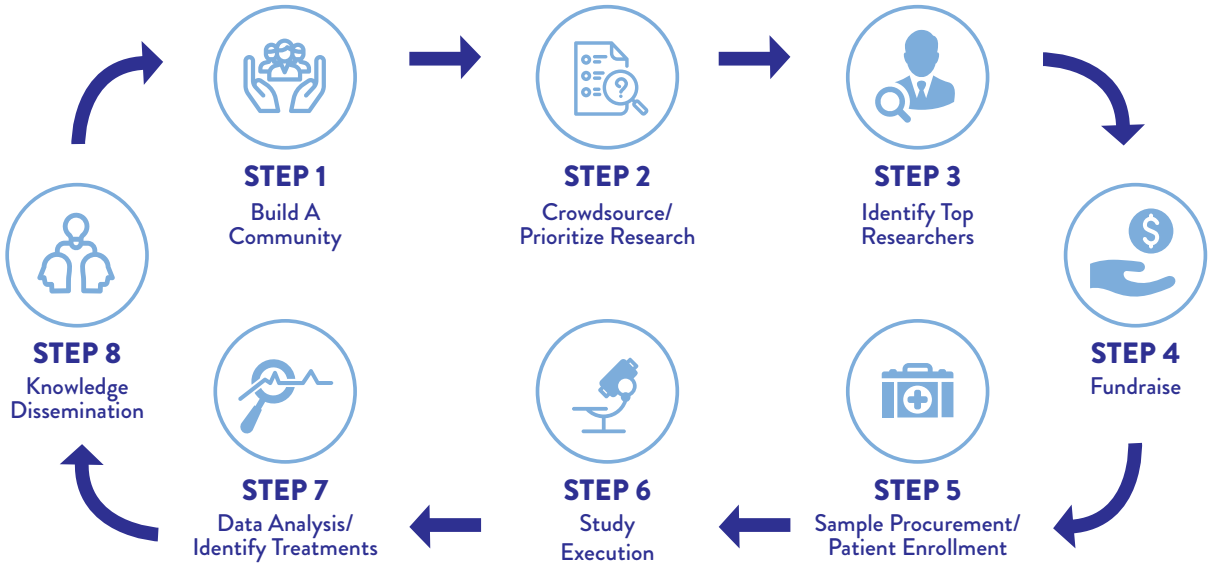
Challenges Within Biomedical Research Community

- The traditional model for advancing research generally involves reseach organizations raising funds and then inviting individual researchers to apply to use the funding in any way the researchers determine.
- Research is not done as part of an overarching strategy.
- Projects don't necessarily build on other projects.
- Competition for limited funding prevents collaboration.
- Few communication tools exist for researchers to connect with one another.
- Patients are often not included in discussions of research.

The CDCN strives 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.

8-STEP APPROACH TO RESEARCH

Out of necessity, focus, determination, and drive, the Castleman Disease Collaborative Network created an 8-step model that builds community, prioritizes goals, accelerates research, speeds trials, and disseminates information to patients, specialists, and policymakers. The 8-step approach to research has served as a model for other grassroots organizations fighting disease.



STEP 1: Build A Community

CDCN has developed a global community of physicians, researchers, patients, and loved ones to accelerate CD research, treatments, and patient care.

- Connected 800+ physicians and researchers
- Assembled a Scientific Advisory Board: 30 experts, 7 countries
- Brought together 1200+ patients and loved ones

STEP 2: Crowdsource/Prioritize Research

CDCN leverages community to crowd-source disease research and prioritize studies into the International Research Agenda.

- Responsive to patient priorities
- Identifies and prioritizes studies
- Supports with funding and resources

STEP 3: Identify Top Researchers

CDCN recruits and engages leading researchers on study priorities.

- Aligns researcher skill set with studies

STEP 4: Fundraise

CDCN performs targeted fundraising to enable specific studies.

- Gala events and campaigns
- Individual donations
- The Castleman Warrior Program
- Collaborative foundation and corporate partnerships

STEP 5: Sample Procurement/Patient Enrollment

CDCN works with patients and physicians around the world to collect the necessary research samples, patient medical data, and/or enroll patients into drug trials.

- Active patient recruitment and participation

STEP 6: Study Execution

CDCN assists with all aspects of successful execution of each study.

- Establish research agreements
- Coordinate contracts among collaborators
- Provide project management support
- Contribute scientific advice

STEP 7: Data Analysis/Identify Treatments

CDCN works with collaborators to ensure rapid analysis.

- Coordinates and synthesizes data
- Helps generate peer-reviewed papers on study results
- Searches for existing drugs that may be effective treatments based on research findings
- Advances clinical trials of promising drugs

STEP 8: Knowledge Dissemination

CDCN helps to quickly disseminate findings to researchers, physicians, patients and families.

- Facilitates physician/researcher meetings
- Hosts annual in-person patient summits
- Shares findings with community, repeating the information cycle

WHAT IS CASTLEMAN DISEASE?

A group of three immune system disorders that share a similar lymph node appearance under the microscope, but have different symptoms, causes, and treatments.

1. UCD

unicentric Castleman disease

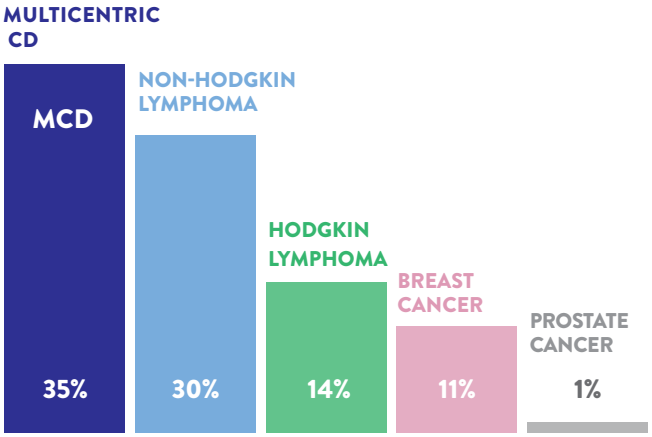
2. HHV-8+MCD

HHV-8-associated multicentric Castleman disease

3. iMCD

HHV-8-negative/idiopathic multicentric Castleman disease

As Deadly As Cancer 5-YEAR MORTALITY RATE



UCD is diagnosed when characteristic features are observed in a biopsied lymph node and there is only one region of enlarged lymph nodes. HHV-8+MCD is diagnosed when characteristic features are observed in a biopsied lymph node, HHV-8 is detected in the lymph node, and there are multiple regions of enlarged lymph nodes. iMCD is diagnosed using the new CDCN-led criteria (Fajgenbaum et al, Blood, 2017) which requires characteristic features in the biopsied lymph node, negative HHV-8 testing, multiple regions of enlarged lymph nodes, specific clinical abnormalities, and exclusion of diseases that can mimic iMCD.[1]

HOW IS CASTLEMAN DISEASE RELATED TO THE IMMUNE SYSTEM?

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 home base 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.

COMMON CASTLEMAN DISEASE SIGNS AND SYMPTOMS

LIVER DYSFUNCTION
May include an enlarged liver, low albumin, and fluid accumulation

FLU-LIKE SYMPTOMS
Such as fevers, night sweats, fatigue, and weight loss

ANEMIA
Low red blood cells or low hemoglobin

KIDNEY DYSFUNCTION
Can contribute to low albumin; is reflected by elevated creatinine

HYPERGAMMAGLOBULINEMIA
Elevated antibodies in the blood

FLUID ACCUMULATION
Low albumin levels cause edema, pleural effusions, and ascites (fluid in belly)

ELEVATED C-REACTIVE PROTEIN LEVELS
A marker of inflammation and CD activity

VERY LOW PLATELETS OR VERY HIGH PLATELETS
Tiny blood cells that help your body form clots to stop bleeding

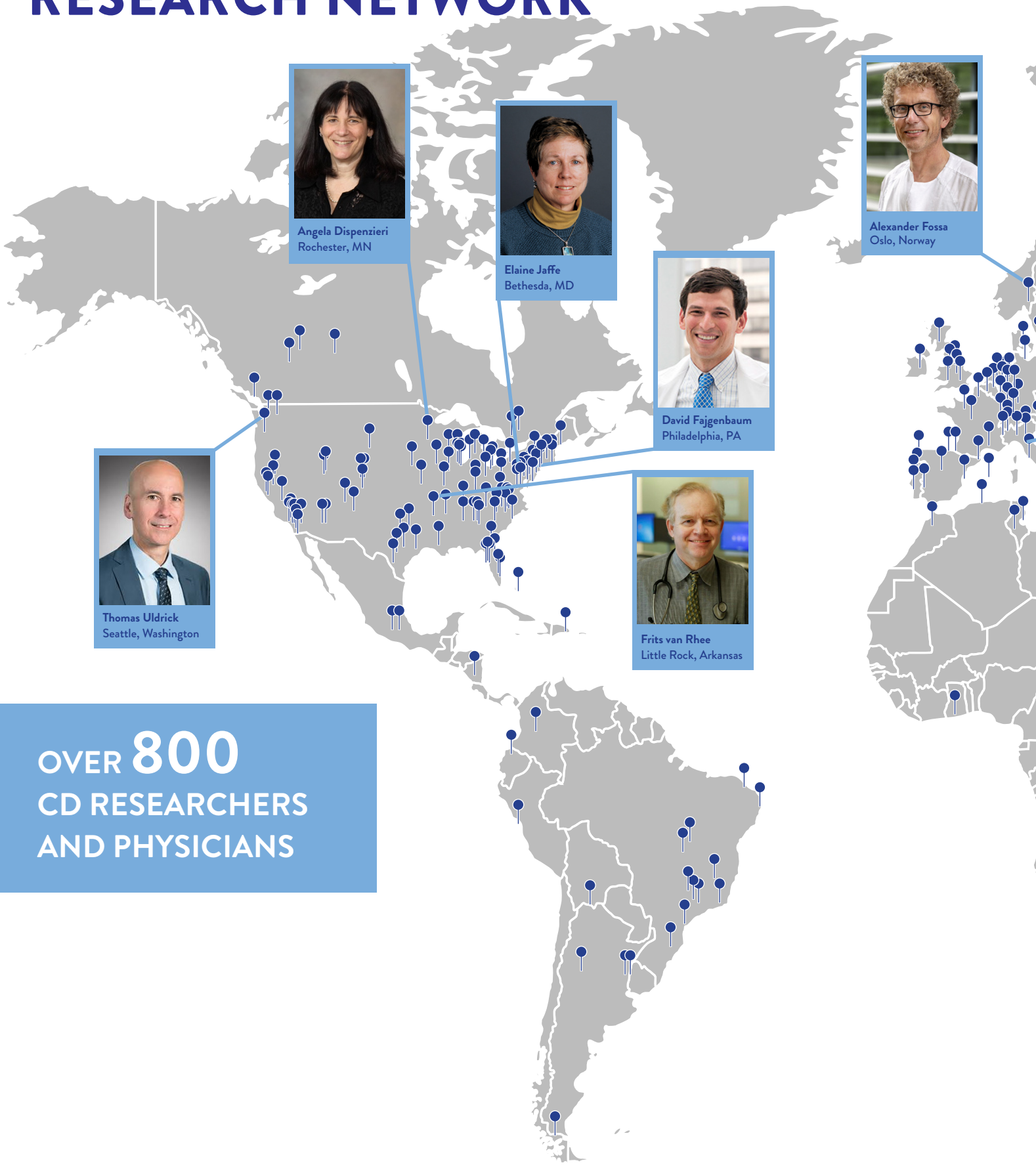
LYMPH NODE
- Enlargement of lymph nodes in multiple regions in MCD
- Enlargement of lymph nodes in only one region in UCD

3 SUBTYPES OF CD

	UNICENTRIC CASTLEMAN DISEASE (UCD)	HHV-8-ASSOCIATED MULTICENTRIC CD (HHV-8+MCD)	IDIOPATHIC MULTICENTRIC CASTLEMAN DISEASE (IMCD)
% OF CASES	50%	25%	25%
REGIONS AFFECTED	Enlarged lymph node(s) in one region	Multiple regions of enlarged lymph nodes	Multiple regions of enlarged lymph nodes
COMMON AGE OF DIAGNOSIS	Mostly children and young adults, but it can occur at any age	Can occur at any age	Can occur at any age
GENDER	Slightly more common in females	More common in males	Slightly more common in males
SYMPTOMS	Usually has no symptoms, but there can be discomfort associated with an enlarged lymph node and occasionally MCD-like symptoms	Wide range from mild flu-like symptoms to severe episodes of sepsis-like, life-threatening organ failure and death	Wide range from mild flu-like symptoms to severe episodes of sepsis-like, life-threatening organ failure and death
CAUSES	Unknown	HHV-8 triggers the disease, and patients are often already immunocompromised (e.g., from HIV or organ transplantation)	Unknown
TREATMENT	Surgery. Some patients may require treatments used primarily for MCD if removal of the lymph node is not possible. UCD patients with paraneoplastic pemphigus need additional treatments.	Can be controlled well with B-cell depletion therapy with rituximab, but cytotoxic chemotherapy is sometimes also needed.	Guidelines recommend anti-IL-6 therapy (e.g., siltuximab, tocilizumab) with or without chemotherapy (e.g., cyclophosphamide, rituximab) and/or immunosuppressants, if needed.[4]
CHANCE OF RELAPSE	Rare	With close monitoring, less common than iMCD	Common, but varies depending on treatment used
CURE	With surgical removal, most patients are cured and will never have a recurrence. There are no reported cases of UCD turning into MCD.	None yet. We need your help to find it!	None yet. We need your help to find it!
5-YEAR SURVIVAL RATE	95%[2] - 1 in 20 patients die within 5 years. Most UCD deaths are in patients who are also diagnosed with paraneoplastic pemphigus or a blood cancer.	65%[3] - 1 in 3 patients with MCD die within 5 years (study did not separate into HHV-8-positive or negative), but new data shows a 90% 5-year survival rate for HHV-8-positive MCD patients treated with rituximab.	65%[5] - 1 in 3 patients with MCD die within 5 years (study did not separate into HHV-8-positive or negative).

[1] *Fajgenbaum DC, Uldrick TS, Bagg A, et al. International, evidence-based consensus diagnostic criteria for HHV-8-negative/idiopathic multicentric Castleman disease. Blood. 2017;129(12):1646-1657.*
[2] *Talat N, Belgaumkar AP, Schulte KM. Surgery in Castleman's disease: A systematic review of 404 published cases. Ann Surg. 2012;255(4):677–684.*
[3] *Bower M, et al. Clinical features and outcome in HIV-associated multicentric Castleman's disease. J Clin Oncol. 2011;29 (18):2481–2486.*
[4] *van Rhee, F., Voorhees, P., Dispenzieri, A. et al, International, evidence-based consensus treatment guidelines for idiopathic multicentric Castleman disease. Blood. 2018;132:2115-2124.*
[5] *Dispenzieri A, et al. The clinical spectrum of Castleman's disease. Am J Hematol. 2012;87:997–1002.*

LEADERS AMONG OUR GLOBAL RESEARCH NETWORK



OVER 800
CD RESEARCHERS AND PHYSICIANS

Pier Luigi Zinzani
Bologna, Italy

Lu Zhang
Beijing, China

Kazuyuki Yoshizaki
Osaka, Japan

David Simpson
Auckland, New Zealand

IN OVER 64 COUNTRIES ALL OVER THE WORLD

RESEARCH PIPELINE

The causes of Castleman disease are still unknown, but thanks to the CDCN's global network of physicians, scientists, and patients, progress has been made to uncover the framework and several components of Castleman disease. The CDCN continues to study Castleman disease to help uncover what is occurring in patients to find better treatments and diagnostic tests in order to continue saving lives.

What is the cause of the immune system hyperactivation in Castleman disease?

In a healthy person's body, inflammatory proteins called cytokines are released when an infection is detected and return to normal once the infection subsides. In CD patients, there is an excessive release of cytokines that occurs for an unknown cause. The elevated cytokines cause immune cells to multiply which leads to CD symptoms. We suspect this immune system hyperactivation is caused by an inherited genetic mutation, a genetic mutation acquired during the course of life, autoimmune mechanisms, and/or an unidentified infection.

What type of immune cells are activated?

In CD, immune system hyperactivation leads to the release of cytokines. We do not yet know which immune cells are responsible for prompting the immune hyperactivation. Our early research findings suggest that T lymphocytes, B lymphocytes, and follicular dendritic cells may be playing important roles in the onset of CD.

What pathways in the cells are activated?

In order for immune cells to produce cytokines, communication lines called pathways must be activated. We don't know which cellular pathways are activated in CD, but we are working hard to uncover these dysfunctional cellular pathways.

What factors are released by the activated immune cells?

We know a few cytokines that play an important role in CD, such as Interleukin-6, but we suspect that other cytokines may also be involved. We are striving to uncover the immune factors released in CD to ultimately find better treatments and diagnostic tests in order to save lives.

What treatments are most effective at stopping Castleman disease?

While we know of a few treatments that are helpful for CD patients, including one FDA-approved drug for idiopathic multicentric CD (siltuximab), these treatments, unfortunately, do not help all patients. We are working to find new and more effective treatments for CD patients that don't benefit from existing options.

RESEARCH HIGHLIGHTS

The CDCN has been working hard to prioritize and conduct high-impact research for Castleman disease since 2012. Check out a few of our recent publications below:

- The first-ever International Diagnostic Criteria for idiopathic multicentric CD
  Published in the journal *Blood,* 2017

- The first-ever International Treatment Guidelines for idiopathic multicentric CD
  Published in the journal *Blood,* 2018

- The SPEED-I (Serum Proteomics Evaluation for Etiology and Pathogenesis Data I) Study
  Published in the *American Journal of Hematology,* 2018
  This study examined 1,129 proteins to investigate which ones may play a role in Castleman disease.

- The discovery of mTOR as a novel therapeutic target in iMCD
  Published in the *Journal of Clinical Investigation*, 2019
  This study identified mTOR as a new drug target and sirolimus as a possible new treatment.

RESEARCHER PROFILE

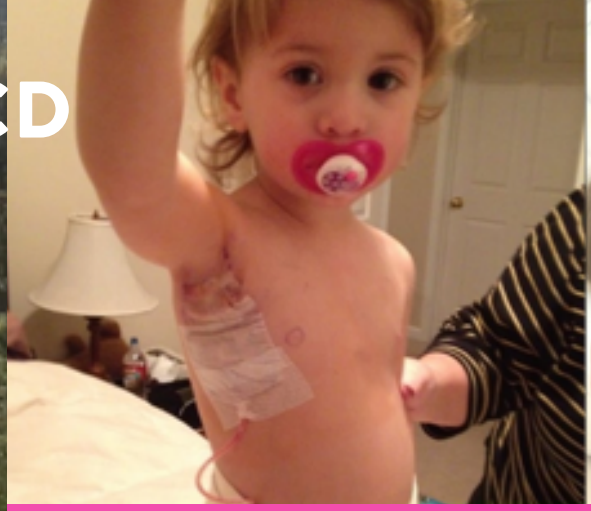
Minji Byun, PhD

Dr. Minji Byun is an Assistant Professor of Medicine at the Icahn School of Medicine at Mount Sinai who has dedicated a significant portion of her early career to researching Castleman disease. Using a special technique called "whole genome sequencing," her research looked at the complete set of genetic material in 14 CD patients to see if there was any common genetic defect among patients with CD. Her first publication from her research described a mutation in the FAS gene in a family who had multiple members with CD. She is now performing further experiments looking at other genes identified from her whole genome sequencing data.

In the true spirit of collaborative research, Dr. Byun made the whole genome sequencing data from the CD patients in her study publicly available. This means that any researcher, with proper ethical approval from their institution, can use the data to conduct their own research to learn even more about CD. All of the data is de-identified and does not contain personal information like names, birthdates, or addresses.

Dr. Byun's research was funded in part by the CDCN's Castleman Warriors, a group of CD patients dedicated to raising money for Castleman disease research. Many patients and family members also contributed samples to this research. We hope that studies like this will continue to inspire researchers, Castleman Warriors, and the greater community to continue to participate and help in the fight against CD.

FACES OF CD



Katie Repasky, **Survivor**

Katie has been battling Castleman disease since she was 18 months old. She at times has had a very difficult battle with her disease, and has undergone several procedures and hospitalizations including multiple surgeries that attempted to remove the grouping of affected lymph nodes. At the time of Katie's diagnosis, there were no clear answers to many questions and there was not a great deal of in-depth data or research available, making the battle for a solution very difficult.

Today she is on sirolimus, which has dramatically improved her quality of life and given her some of her childhood back. The drug is currently being evaluated in a clinical trial as a possible CD treatment, but so far has dramatically and successfully kept Katie's favorite person (Dr. David) in remission for over 5 years. Since starting sirolimus, Katie has remained relatively stable, though, with a weakened immune system, she remains vulnerable.

Victoria Humphries, **Survivor**

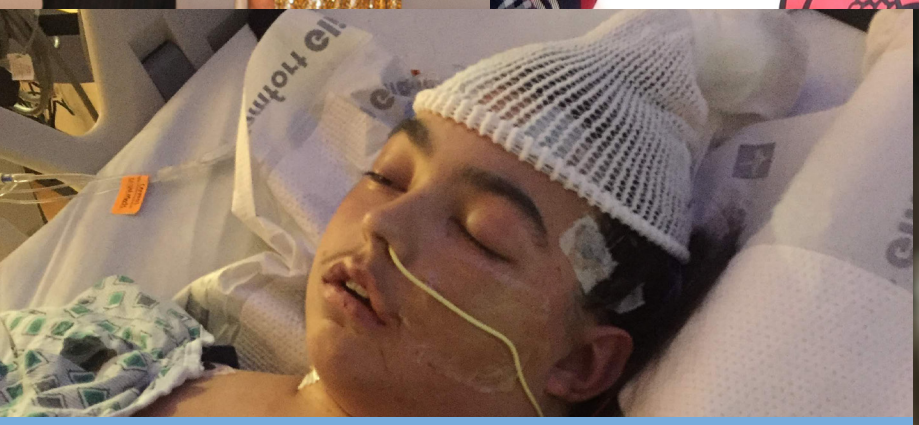
Victoria was diagnosed with idiopathic multicentric Castleman disease with TAFRO syndrome in January of 2016. At the time of her diagnosis, she struggled with many overwhelming emotions: grief, shock, anger, fear, frustration, and loneliness. What scared her the most was a statistic listing a five-year survival rate for patients with idiopathic multicentric Castleman disease. She found the CDCN through an initial search for information on Google.

It was not until she was hospitalized that she learned the true value and importance of the CDCN in her life and battle with CD. Dr. David Fajgenbaum reached out to her family offering insight, understanding, information, and help that would get Victoria the best care she could have. Treatment with siltuximab led to a rapid improvement in her health. She has since joined the Warrior team which gives her a sense of fighting back, doing her part to help find a cure, and the ability to help other patients.

Yankee McKinnon, **Survivor**

Before Yankee was diagnosed with Castleman disease, she considered herself to be super happy and carefree. But she had a harder and harder time keeping weight on, and she felt constantly fatigued. In early 2018, she became unable to walk and had a high fever, and she was immediately admitted to the hospital. Shortly after her diagnosis, she was connected to the CDCN and Dr. Frits Van Rhee, who treated her with siltuximab and helped her to get her life back. With her husband and family at her side, Yankee says she has the support she needs to be a Castleman Warrior.

Yankee says that finding the CDCN and the people associated with the organization was a blessing and she thinks it's important for everyone to advocate for themselves and join the amazing CDCN team. "We share our good days and bad days," she says. "We support each other, laugh and cry. We are not alone, we are fighting our battles together every day. I have a mission to be strong and to continue to support my Warriors—to live! We might lose some battles, but we will win the war!"



Joey Incorvia, **Survivor**

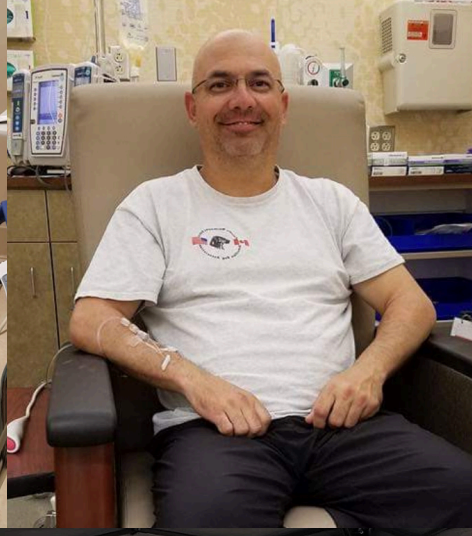
Joey was diagnosed with idiopathic multicentric Castleman disease with TAFRO syndrome in October of 2018. He was hospitalized for almost 3 months at Children's Hospital of Philadelphia with kidney injury, an enlarged spleen and liver, fevers, and fluid retention in his abdomen. The Children's Hospital team reached out to Dr. David Fajgenbaum who was able to help them get a definitive diagnosis and advise on a treatment plan right away, which included sirolimus and led to significant improvement.

Joey's family was able to connect to the CDCN team within an hour of Joey's diagnosis. His parents encourage anyone and everyone to get involved and provide support to the organization and all the good work they do. Joey's family says that the CDCN "continues to be a great source of information, hope, and comfort for us."

Ryan Hoke, **Survivor**

When Ryan first became ill, he had lost a lot of weight and was fighting what appeared to be a severe lung/sinus infection. He was twice admitted to the hospital with severe stomach pain, prompting misdiagnoses from pancreatitis and fibromyalgia to lymphoma. A battery of blood tests followed, and he was later informed that what he was suffering from was Castleman disease. In searching for answers and more information about Castleman disease, he found the CDCN.

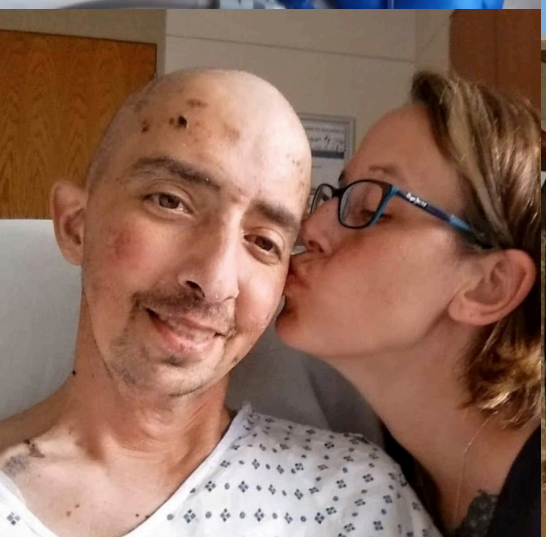
He learned about the CDCN patient summit and decided to make the trip to Philadelphia to learn more. There he met other patients for the first time, and witnessing a group of people working hard to find out more about the disease gave him a renewed sense of hope. “After my first patient summit trip, I felt like I would survive this disease,” Ryan says. “I had hope because I was taking the steps to fight it and working with an organization that was fighting alongside me.”



Gary Gravina, **Survivor**

Before Castleman disease entered his life, Gary was a healthy, active guy, with a background in the military and 27 years as a carpenter. In just a few days, he says, Castleman disease had him on a ventilator struggling to breathe and fighting for his life. The fight from the hospital room back to a life he can enjoy was the hardest he has ever known. And he credits Dr. David Fajgenbaum and the CDCN as being directly responsible for the diagnostic criteria that his doctors used to diagnose his CD, which started him on the path toward treatment and recovery.

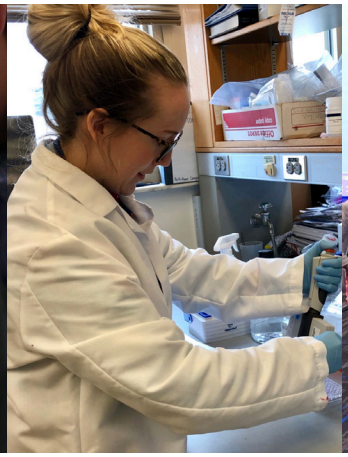
“As a former Marine, I know what it’s like to volunteer for something that could kill me,” says Gary. “What I’d never experienced was volunteering for something that could save my life, and it was David and the CDCN who first offered me the opportunity to do that.”



CSTL: CASTLEMAN DISEASE CENTER AT THE UNIVERSITY OF PENNSYLVANIA

Co-Founder of the CDCN, Dr. David Fajgenbaum, recently started the Center for Study & Treatment of Castleman & inflammatory Lymphadenopathies (CSTL) at the University of Pennsylvania, the first Center integrating top-notch clinical care, clinical trial opportunities, and basic, translational, and clinical research. Drs. Adam Cohen and Sunita Nasta provide world-class patient care. The Center is leading a clinical trial of a new treatment for idiopathic multicentric Castleman disease called sirolimus. Patients have the opportunity to contribute samples to cutting-edge research through Castlebank and their data from medical records to the ACCELERATE Registry. Dr. Fajgenbaum is proud to lead the Center as both a physician-scientist and patient to advance treatments and cures for Castleman disease.

The CSTL includes a number of dedicated researchers at various stages of their careers that dedicate their time and resources to better understanding and treating Castleman disease. Information about a few of the immunology researchers in the CSTL currently working on Castleman disease is provided below.



UNIVERSITY OF PENNSYLVANIA RESEARCHERS

Dr. Taku Kambayashi is an immunology expert who became involved with Castleman disease research after the CDCN was established in Philadelphia. His research has involved helping to find out if there is a common change in an inflammatory gene among patients with CD and will help learn if there are genetic causes for CD. He also is investigating the role of a key immune cell called a T-cell in CD.

Ruth-Anne Langan is a PhD student in immunology who is co-mentored by Drs. Fajgenbaum and Kambayashi. Her exciting research uses a special technique called single-cell RNA-sequencing aimed to identify cell types and pathways that can be targeted for new treatments.

Ruth-Anne has also been working closely with **Dr. Alberto Japp**, a postdoctoral immunology researcher who was inspired to research CD after meeting Dr. Fajgenbaum. His research focuses on autoimmune disorders and about how the immune system may be playing a role in CD. The CDCN has been excited to see the progress that this collaborative team has made so far, and hopes that the interdisciplinary Center will continue to inspire collaboration between researchers across various stages of development.

JOIN THE FIGHT AGAINST CD

Contribute medical data to the ACCELERATE Natural History Registry

The CDCN launched ACCELERATE, the first-ever global patient registry for CD, in 2016 to combine 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 themselves online in 15-20 minutes. Deceased CD patients can also be enrolled by their surviving family members. For more information and to enroll online, visit: **www.cdcn.org/accelerate** or call **215-349-5713**.

Donate your samples to research through the CastleBank

A shortage of blood and lymph node samples from patients is slowing down research. The CDCN launched CastleBank to make it easy for patients to share their blood samples or excess lymph node tissue samples (from a clinical procedure) for research in order to find cures for Castleman disease. The CDCN covers all shipping and all logistics. Patients consent to providing samples by telephone or email. If you are newly diagnosed, experiencing active symptoms, or have a lymph node biopsy scheduled, please email **info@castlemannetwork.org** or call **267-586-9977**. You can also express your interest in contributing samples in the future at **www.cdcn.org/samples**.

Donate to the CDCN!

Everyone can join the fight by donating to high-impact research.

- Donate to life-saving research online at **www.cdcn.org/donate-here**
- Prefer to send a check by mail? Make out to: "CDCN" or "Castleman Disease Collaborative Network" and send to:
  Castleman Disease Collaborative Network
  P.O. Box 3614
  Paso Robles, CA 93447
- EIN 37-1510354
- Questions? Call **610-304-0696**

PATHWAY TO A CURE

The CDCN has several priorities for 2019-2020, which guide the path to a cure for Castleman disease.

1

Patient Engagement

A core mission of the CDCN is to support, empower, and educate patients and loved ones affected by CD. From our annual Patient Summit that brings together the CD community to our 24/7 patient and loved ones support phone, we do everything we can to help CD patients.

2

Collaborative Research

The CDCN works to prioritize, facilitate, and execute collaborative research with expert physicians and researchers from around the world. CD experts are currently spearheading over 15 studies and are collaborating to write the first-ever diagnostic criteria and treatment guidelines for unicentric CD.

3

ACCELERATE Registry and CastleBank Biobank

Our goal is to enroll 100 patients into the ACCELERATE registry and collect 100 samples from CD patients each year. Data and samples collected in ACCELERATE and the Biobank are thoughtfully used for high-impact research studies.

4

Events and Campaigns

We strive to lead events and campaigns to raise $200,000 per year to support CD research. Our campaigns include World CD day, our annual Quest for a Cure event, and many more.

5

Physician Engagement

The CDCN leads the effort to educate the worldwide medical community about CD and identify experts in CD for our referral list. We ensure that the most accurate information about diagnosing and treating CD is available on physician education platforms so that physicians have access to the best medical practices when treating CD patients.

6

Supporting Clinical Trials

In Summer 2019, the University of Pennsylvania launched the first USA clinical trial in over 5 years for a new treatment for CD, sirolimus. Patients with treatment-refractory idiopathic multicentric CD can enroll at the University of Pennsylvania and the University of Arkansas for Medical Sciences.
Email CDtrial@pennmedicine.upenn.edu or call 267-586-9977 for more information.

7

Individual and Corporate Partners

We foster relationships with individual donors and corporate partners to raise $200,000 per year for CD research. We strive to deepen and expand these relationships so that we can continue to fund life-saving CD research.

8

Communications

The CDCN focuses on leveraging communication outlets to support our 2019-2020 goals. We work hard to share our amazing progress with the community.

9

Volunteer Engagement

Our organization was started and built by an incredible group of hard-working volunteers, and we continue to recruit and retain top talent and volunteers to support the mission of the CDCN.

10

Expanding the CDCN's Approach to Other Rare Diseases

The CDCN has partnered with the Chan Zuckerberg Initiative (CZI) to build a set of tools to help share our Collaborative Network Approach with other rare disease research organizations. We hope that our partnership and work with CZI will help accelerate research for Castleman disease and other rare diseases.

CDCN
LEADERSHIP

David Fajgenbaum
MD, MBA, MSc
Co-Founder & Executive Director

Mary Zuccato
MBA
Chief Operating Officer

Frits van Rhee
MD, PhD
Co-Founder & Co-Chair of Scientific Advisory Board

Jason Ruth
PhD
Chief Scientific Officer

Mileva Repasky
MS
Chief Patient & Development Officer

Sheila Pierson
MS
Director of Registry Enrollment

Sophia Parente
Chief of Staff
Biomedical Leadership Fellow

Daniel Arenas
PhD
Biomedical Leadership Fellow

Rozena Rasheed
Biobank Coordinator

Patty Prazenica
Co-Director of Development

Raj Jayanthan
MD
Senior Patient Engagement Advisor

Colin Smith
PhD
Director of Collaborative Research

Caitlin Fajgenbaum
Strategic Communications Advisor

Board of Directors

In 2012, the CDCN merged with Castleman's Awareness & Research Effort (CARE), which was founded in 2007 and laid the groundwork for their combined success. The CDCN Board of Directors is led by several members of the original CARE Board as well as new members:

Greg Pacheco, Co-Founder of CARE & Board President of CDCN; Vice President of Operations at BH & TF Inc. Greg is a CD survivor.
JC Diefenderfer, Board Vice President; Winemaker at Hope Family Wines; JC is a close family friend of Greg Pacheco's and was a member of the founding Board.
Charlyn Pacheco, Co-Founder of CARE & Board Secretary of CDCN; Charlyn is Greg Pacheco's wife and has helped to lead several CD fundraising efforts in Paso Robles, CA.
Michael Stief, Board Treasurer; Operations Manager at Black's Hatchery & Turkey Farm; Michael is a close family friend of Greg Pacheco's.
Kim Driscoll, Board Member & Founder of the inaugural ELYSESTRONG Roar for a Cure; Kim is the mother of Elyse Driscoll, who sadly passed away battling CD when she was only 13 years old.
David Fajgenbaum, MD, MBA, MSc, FCPP; Board member; Co-Founder & Executive Director of the CDCN; Assistant Professor of Medicine in the Division of Translational Medicine & Human Genetics at the University of Pennsylvania; David is a CD survivor.
Bette Jacobs, PhD; Board member; Professor of Health Systems Administration at Georgetown University; Distinguished Scholar and Co-Founder at the O'Neill Institute for National and Global Health Law; Fellow and Visiting Professor at Campion Hall at University of Oxford
Kevin Silk, JD; Board member; Associate, Dechert LLP

Advisory Council Members

Marjorie Raines, Former Executive Vice President and Chief Investment Officer at The Chubb Corporation
Marc Brownstein, President and CEO of the Brownstein Group
Laura Bessen-Nichtberger, Former Executive at Bristol-Myers Squibb and Medical Doctor
Bernie A. Prazenica, President and GM of WPVI-TV/6abc Philadelphia
Ryan Hummel, Executive at Vynamic
Tony Forte, Partner, Saul Ewing LLC

Leadership Team

The CDCN has made major strides with the guidance of a leadership team composed of more than 35 patients, loved ones, medical students, recent MD graduates, PhD students and recent graduates, and MBA students and recent graduates.

Special Thanks

Marjorie Raines
Glen de Vries & Medidata Solutions
Elana Amsterdam
Christopher Barillas, Kaarina Mackenzie & Athena Global Advisors
And all of the amazing patients, loved ones, physicians, researchers, and donors who are part of this fight.

Scientific Advisory Board

The CDCN's first priority was to assemble the top global experts on CD onto a Scientific Advisory Board that sets the overall direction of the CDCN and prioritizes research. Currently, the CDCN includes members representing seven countries, including the United Kingdom, United States of America, Norway, Japan, France, New Zealand, and China.

Corey Casper, MD, MPH; University of Washington
Amy Chadburn, MD, FCAP; Cornell University
Shanmuganathan Chandrakasan, MD; Cincinnati Children's Hospital
Angela Dispenzieri, MD; Mayo Clinic
Kojo Elenitoba-Johnson, MD; University of Pennsylvania
David Fajgenbaum, MD, MBA, MSc, FCPP; CDCN, University of Pennsylvania
Alexander Fossa, MD, PhD; Oslo University Hospital
Makoto Ide, MD, PhD; Takamatsu Red Cross Hospital, Japan
Elaine Jaffe, MD; National Institutes of Health
Vera P. Krymskaya, PhD, MBA; University of Pennsylvania
Razelle Kurzrock, MD; UC San Diego Moore's Cancer Center
Mary Jo Lechowicz, MD; Emory University
Megan Lim, MD, PhD; University of Pennsylvania
Ivan Maillard, MD, PhD; University of Pennsylvania
Nikhil Munshi, MD; Harvard University
Sunita Nasta, MD; University of Pennsylvania
Eric Oksenhendler, MD; Hôpital Saint-Louis in Paris, France
Jean-Francois Rossi, MD, PhD; University Hospital of Montpellier, France
Arthur Rubenstein, MBBcH; University of Pennsylvania
Jason Ruth, PhD; Director of Translational Research at the CDCN
Steve Schey, MD; King's College Hospital
David Simpson, BHB, MBChB, FRACP, FRCPA; North Shore Hospital, NZ
Gordan Srkalovic, MD, PhD; Michigan State University
Matthew Streetly, MD; King's College Hospital
Tom Uldrick, MD, MS; National Institutes of Health
Peter Voorhees, MD; UNC Comprehensive Cancer Center
Frits van Rhee, MD, PhD, MRCP (UK), FRCPath; CDCN, University of Arkansas
Raymond Wong, MBChB, MD, MRCP(UK), FHKCP, FHKAM(Medicine); Hong Kong
David Wu, MD; University of Washington
Kazuyuki Yoshizaki, MD, PhD; Osaka University, Japan

CASTLEMAN DISEASE COLLABORATIVE NETWORK

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