

SPECIAL
POINTS OF
INTEREST:

- Welcome to CADdy News!
- Introduction to the CADF
- How to cope with COVID-19
- Sutimlimab therapy update
- Guest blogger Dr. C Connolly

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CADdy NEWS

VOLUME 1, ISSUE 1

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Welcome to our first edition!

Welcome to the first edition of CADdy News! The goal of this newsletter is to share resources, information and research updates that will be useful to persons with Cold Agglutinin Disease and their care partners. It will be a place where we can inform, entertain and support those living with CAD.

We've chosen a bright, summery color theme to share the warmth, and we plan to release four editions per year to keep you up to date with all the latest CADdy News!

Topics discussed in our first edition include: COVID-19, the CAD Foundation, a therapy update on Sutimlimab, and a product review with a prize to be won!

We also introduce our guest blogger, Dr Catherine Connolly, who will be sharing her experience from both a doctor and care partner's perspective.

If you have CADdy questions you'd like answered, or information you'd like to share, we're keen to hear from you! Our contact information is listed on the back page.

Until next time, stay warm!

Who are we?

In 2007, founding member and 'CADdy' Betty Usdan formed the website: coldagglutinin.org to serve as a hub of information, support and encouragement for CAD patients and care partners globally. From these connections emerged CADdy CHATTER – a popular Facebook group of over 1000 CAD patients and their care partners which enables direct information sharing and immediate support to persons living with CAD. The Cold Agglutinin Disease Foundation Inc. was officially registered in 2019 as a non-profit corporation. Its mission is to create a healthier life for the greater CAD community . We do this by filling in the information gaps which exist for patients, care partners, primary physicians, hematologists, nurses and lab technicians.



Understanding through experience: Cold Agglutinin Disease

Dr. Catherine Connolly

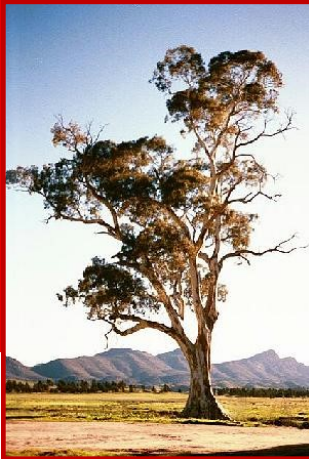
My father has been living with Cold Agglutinin Disease for the last 4 years – a rare condition that leads to the breakdown of red blood cells when he’s exposed to cold weather. In this blog series I explore his disease from the personal side and the professional side, as his daughter and as a qualified medical doctor. Through telling our story, piece-by-piece, I hope to raise awareness, share knowledge, and build friendships within the CAD community.



There are worse places to have CAD than sunny Australia!

“This purple hue is known as acrocyanosis”

The famous Cazneau Tree in the Australian Flinders Ranges



Part 1: Going Purple

My Dad’s diagnosis of CAD was a long drawn out process rather than a definitive moment in time. We don’t know exactly when it started, but we gradually observed how his nose and ears became noticeably purple whenever the weather was cold. He had already put up with Raynaud’s phenomenon (fingers appear white due to decreased blood flow when cold) since he was young and my Mum was forever telling him to put a coat on, or gloves, or a hat. She still does! Dad lives and works in a rural town in Australia. He’s been described by some as a ‘workaholic’, but he’s always been full of energy and likes to keep busy and keep fit. One of his habits was to go for an early morning ocean swim, which he always loved. Our nearest neighbour across the sea is Antarctica, so the water can be very cold in the winter – colder even than the Irish Sea where Dad used to swim while he was growing up.

After one fairly brisk swim, with the wind blowing strongly, Dad emerged from the sea looking a peculiar colour of blotchy purple and yellow. His nose, ears and fingertips were a dusky purple hue. It turned out that he had noticed this before and thought he had some weird rash, but then the purple hue began to reappear more frequently. On most Friday nights at field hockey during the winter, his purple nose would be such a deep colour that other parents huddled on the sidelines would comment on it. None of us realised that this heralded the start of Dad’s CAD – we just thought he was cold and needed to put

his beanie on. This purple hue is known as acrocyanosis, and in Dad’s case it was apparent for several years before we arrived at a diagnosis of CAD.

Now that we know he’s got CAD, his purple nose is a serious sign that his red blood cells are clumping together and he needs to cover up and get warm quick. It’s very difficult to manage because although he has made an effort to put on extra clothes these days, he doesn’t always feel cold and he can’t tell when he’s turning purple. He likes being out in the garden and going for runs, and long walks, but all of these activities put him at serious risk during the winter months, as the cold temperatures settle on any bit of exposed skin. Even the air he breathes can prove too cold and affect his lungs. It’s hard to live with because even mild temperatures mean he has to go out dressed with a balaclava, gloves and a jacket, when most people wear light clothing and T-shirts. For Dad, giving up swimming, ParkRun in the winter, and long walks when it’s chilly, has been hard to deal with mentally and physically.

In this blog, I hope to address various aspects and symptoms of Cold Agglutinin Disease through the experiences of my Dad. Because of my medical background, I will aim to include a short explanation of the symptoms I’ve described at the end of each post. Part 2 explores how Dad’s busy life full-of-energy has had to reduce as he comes to terms with another major symptom of this disease – fatigue.

Part 1: Going Purple (cont.)

Medical Spotlight: Acrocyanosis

Acrocyanosis, colloquially referred to as “going purple” amongst the CAD community, is a common complaint for patients. However, this symptom is not exclusive to CAD and it may occur with other medical conditions too. It is usually painless and affects the extremities, such as the ears, nose, hands, and feet. While the exact mechanism of acrocyanosis is not entirely understood, in CAD it is closely linked with the cold agglutination of red blood cells, which occurs in tiny blood vessels in the peripheries of the body. As blood circulates to the peripheral areas of the body it’s exposed to colder temperatures. This slows down the movement of red blood cells, and permits the binding of the CAD antibody to them. One CAD antibody usually binds to many red blood cells at a time, leading to a clumping effect. This, combined with antibody-induced damage to red blood cells, can decrease the amount of oxygen delivered to peripheral tissues and result in a purple or blue discolouration.



“His nose, ears and fingertips were a dusky purple hue”

Therapy update: Sutimlimab

Sutimlimab selectively blocks the complement protein C1s. This means that the red blood cells which are overzealously tagged for destruction in the cold peripheries of a CAD person will no longer be destroyed by the complement system. The complement system is a body system which destroys unhealthy cells (usually cells infected with bacteria). Treatment with this therapy is expected to result in an increased in blood count levels for persons with CAD.

In May 2020 the U.S. Food and Drug Administration (FDA) granted a priority review of Sanofi’s application to list Sutimlimab for the treatment of

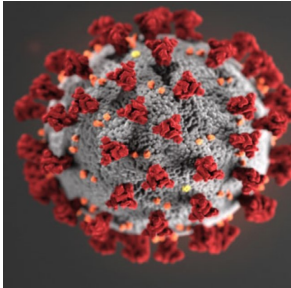
adult patients with CAD. The expected date for the FDA’s decision is 13 November 2020. The application is based on results from the CARDINAL and CADENZA clinical trials. More information about these trials can be found on the CADF website.

Of note, although Sutimlimab blocks one aspect of the immune system (the classical complement pathway), this pathway is not critical for the body’s defence against viruses. There is no evidence to suggest patients on this trial medication are more at risk from the novel coronavirus or COVID-19.

**Sutimlimab is a product from
the Sanofi company**

SANOFI 

Novel coronavirus and COVID-19



Within a few short months this pandemic has changed the way we go about our lives. As a person living with CAD, you and your family or care partners will likely have questions and concerns about the novel coronavirus and its associated illness, COVID-19.

Are people with CAD more at risk? Possibly, but this is not just limited to the coronavirus. People with CAD may be more vulnerable to picking up any cold, flu or virus, and can also suffer more complications from these infections due to a weakened immune system.

Here’s our top 5 tips for how to look after your health and wellbeing if you’re feeling uncertainty or anxiety about infections.

Our top 5 tips during coronavirus

Let’s support each other to stay safe and connected during this pandemic



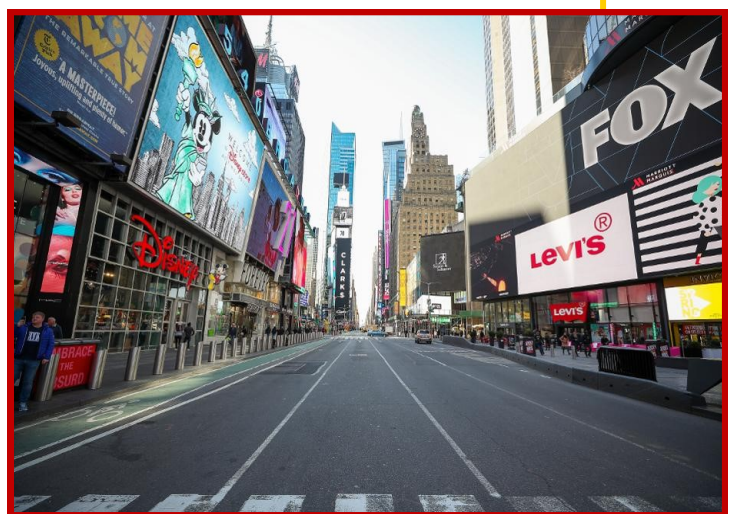
1. Practice good hygiene. Be vigilant with hand-washing, not touching your face and avoiding unnecessary interactions. Wearing a mask can reduce exposure to infected droplets from others.

2. Contact your physician if you’re concerned. Many GPs and treating teams have new processes in place to keep you and their staff safe. You may find it reassuring to know what they’re doing to support you.

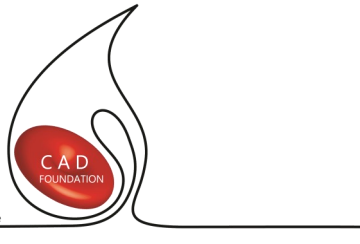
3. Take breaks from news media. Constant pandemic updates can add to your worries. Choose a time once-a-day or less to seek an update from a trusted news source.

4. Have a plan for your medication access. If you’re in a clinical trial, make sure to ask your trial contact person for updates if you are concerned about potential changes to the trial. Remember, they are there to help you and keep you informed. If you are in home isolation, contact your GP or Pharmacy as some sites have started home delivery services to support vulnerable people and those in home isolation.

5. Keep life balanced. Ensure you’re getting enough food, sleep, exercise and enjoyment. Enjoy relaxing activities like reading a book or get creative with a pen and paper or crafts. Don’t forget to keep social using FaceTime, Zoom or phone to communicate with friends and family. It can be helpful to share any worries with others and hear their perspective on how they’re coping.



All is quiet in Times Square



Cold Agglutinin Disease Foundation

E-mail: info@cadfadvocacy.org

Website: <https://coldagglutininindisease.org>

Facebook:

Business page- Cold Agglutinin Disease Foundation

Support group- CADdy Chatter

A non-profit foundation dedicated to creating healthier lives for the CAD community of patients; we are committed to educating them, their care partners and the medical profession about this rare disease.



Complete our online profile at:

<https://form.jotform.com/201154877602050>

to receive up to date information about virtual meetings, events (like the CADF summit), volunteer opportunities, promotion and more!

Product review

OCOOPA* rechargeable hand warmers are a great product to keep your hands warm- they're especially useful for those who suffer with Raynaud's phenomenon. They offer a smooth design which fits comfortably in the palm, perfect to keep in the pockets of your coat while outdoors! On Amazon they score a 4.5 star rating from over 2,000 reviews. They are adjustable with 3 levels of temperature options and a large capacity battery which can also be double as a power bank for your mobile phone.



*no affiliation or promotion to CADF—we just picked it because of the great reviews!

For our first edition we are providing this product as a

FREE GIVEAWAY!

To enter, you need to have completed the **member profile survey** on the CADF website.

Then email: info@cadfadvocacy.org with a suggestion for what topics you'd like covered in future editions of CADdy News!

Head to CADdy Chatter to catch up on more hot tips to stay warm (pun intended)!

*Odds of winning are based on the number of entries received

Entry Deadline: Midnight August 3, 2020.

Draw Date: August 5, 2020