

SPECIAL
POINTS OF
INTEREST:

- COVID-19 vaccination update
- CADdys around the World!
- Guest blogger Dr. C. Connolly
- CADdy Alison's museum photos
- Inaugural Quiz section!

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CADdy NEWS

VOLUME 1 ISSUE 3

DEC 2020



Welcome from the editors!

Welcome to the third edition of CADdy News, the last issue for 2020!

It's been a productive year for the Cold Agglutinin Disease Foundation; we welcomed new staff members, initiated the CADdy News publication, and had our first international Zoom meeting to interact with our members!

We're mindful that it has been a strange, and at times traumatic, year for many who are dealing with the response to COVID-19. Whether or not you've had to confront the health, economic or social impacts of this illness, it's likely that you might know someone who's been affected. We sincerely hope the CADF has been able to provide you with support- either emotional or educational- as we all grapple with adapting to a new way of life.

In this edition, we bring you news from CADdy members around the globe! With travel restrictions in place, we're trying to bring the world to your doorstep! Thank you very much to all those who participated :)

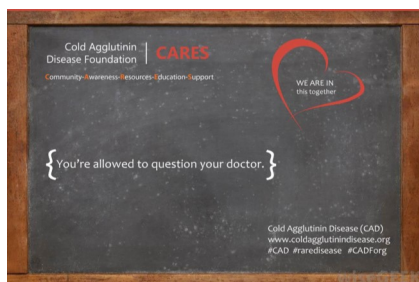
Congratulations go to **Jeannette Thele** who was the winner of the giveaway competition! We hope you enjoy your Gintao heated foot pad! It's a pleasure to feature you in our "Chitter-Chatter" section for this edition.

If you haven't already done so, please complete your member profile at <https://form.jotform.com/201154877602050> This will ensure you get the first release of CADdy News, direct to your email.

Merry Christmas or Happy Holidays, if you're celebrating the season!

Until next time, stay safe and warm!

CADF awareness campaign



This is what CAD looks like!
SHARE TO RAISE AWARENESS

The CADF Chalkboard Campaign has started! Awareness is critical for the CADF to get future funding to hold more Zoom meetings and create partnerships.

Please share the posts with your family and friends, and comment if you feel a post resonates with you.

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.



Kangaroos in the setting sun

“...his yellow skin wasn’t something we could ignore”

Part 3: A different kind of “tan”

Some friends nicknamed me ‘Casper’ – after the ghost – and I have Dad to thank for my very pale, almost translucent, Irish skin tone. We have the sort of skin that’s definitely not well-suited to the blazing Australian sun. But I’m not complaining, because for Dad’s CAD the climate is ideal. We don’t fit the picture of stereotypical Australians with natural bronzed skin, but in the early stages of Dad’s CAD, he developed a different kind of tan. His skin gradually became a yellowish colour and the whites of his eyes were affected too. At first it was so gradual we weren’t even sure he was looking yellow, and it seemed to come and go. We now know that it’s a sign known as Jaundice, and it’s yet another marker that indicates what’s happening in the body of a person who has CAD.

In someone who’s always been fit and healthy, jaundice was a disturbing development. Although Dad was tired, he wanted to keep working so he could feel normal. He’s not the invalid type! But going to work meant people were constantly telling him he didn’t look well, and they were asking other staff members – “Does he have cancer?” “Is he going to take time off?” “Is he retiring soon?” There was something frustrating about people pitying him, and telling him that he looked really sick. They projected a negative outlook without giving him a chance to shape his own perception of living with illness. I think Dad went into denial for a while – telling people he was fine and then working harder than ever at a time when he should have been taking it easier.

However, his yellow skin wasn’t something we could ignore. We were also concerned about his pallor, fatigue, irritable moods, and the people around us asking about cancer. This worrying combination of symptoms and signs meant it was time for some serious investigations. The next blog post will cover Dad’s experience of being investigated for his illness, including blood tests, imaging scans, and a bone marrow biopsy.

Spoiler Alert: What we didn’t expect was that a simple blood test would prove to be the most problematic of these investigations!

Four years on, however, we are now well accustomed to the difficulties of getting a blood test with CAD. We’ll explore this topic next time.

Jaundice, or yellowish discolouration of the skin and/or sclera, happens in CAD because of a build-up of products from the breakdown of red blood cells. Jaundice also happens in association with a whole range of medical problems, some very serious, so it was confronting to witness it when we didn’t yet have a proper diagnosis for Dad’s condition. As well as being varying shades of yellow, he was also paler than usual due to his low Haemoglobin.

The combination of pale, yellow-tinged skin and constant fatigue were worrying signs, all the more worrying when people began to jump to the conclusion that he must have cancer...



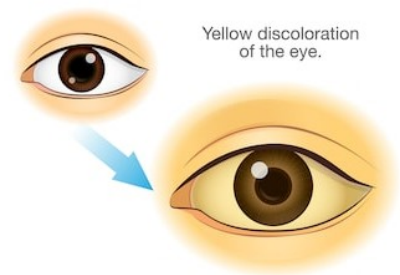
A jaundiced hand

Part 2: A different kind of “tan” (cont.)

Medical Spotlight: Jaundice

Jaundice refers to the yellowish discolouration of skin or sclera (the whites of the eyes), and occurs in response to a variety of medical conditions. Therefore, it’s important to pay attention to other symptoms and signs that coincide with jaundice, in order to work out the cause. In CAD (which occurs when CAD antibodies bind to red blood cells and signal for their destruction by the body’s immune system), jaundice is due to the accumulation of bilirubin, which is a by-product formed from the breakdown of red blood cells (haemolysis). In normal circumstances red blood cells have a lifespan of 3-4months before they are broken down by the body. The protein and iron components are recycled, whilst the pigments are turned into bilirubin and excreted. In fact, excretion of bilirubin products is what’s responsible for the yellow colour of urine. However in CAD the speed at which red blood cells are being broken down sometimes overwhelms the rate at which the body can clean up. During these episodes CADdy’s might notice yellower skin and darker urine. Bilirubin products can be measured on a urine dipstick test, and in the blood. If suspecting a rise in haemolysis, it’s worthwhile to monitor the Haemoglobin level, ensure the body is well rested and nourished, keep warm, and follow the advice of your medical specialist.

**“Bilirubin is a
breakdown
product of RBCs in
CAD”**



“Chitter Chatter”: Meet our members

Name: Jeanette Thele, Vice President of the North American Operations for AXA XL

What 3 words describe you? Athletic (my knees would argue), funny, engaging (I love small talk that ends in a connection).

Who do you most admire and why? My kids. They’re compassionate, smart and a wee bit sarcastic.

How has CAD changed your life (one positive, one negative)?

Positive – I don’t give needles a second look.

Negative – My face changes colors like the seasons when I get cold!

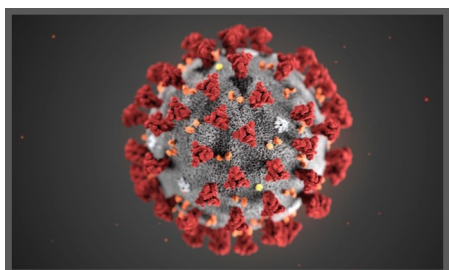
What is your favorite hobby? Playing, watching or talking about sports (especially college football).

What’s one thing that annoys you the most? Politics in the U.S.

What’s the best piece of life advice you’ve heard? From my mother: ‘The squeaky wheel gets the oil’. I’m a little vertically challenged and, as a kid, my mother always told me I needed to be a little more vocal to get what I want or needed.



Novel coronavirus and COVID-19



The novel coronavirus, or severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) is the virus, and COVID-19 is the associated illness.

Here we discuss the soon-to-be-released vaccinations: the scientific steps in their development, common questions, and general advice regarding vaccination in patients with Cold Agglutinin Disease.

Novel coronavirus: *the vaccine*

How do we know if the vaccines are safe?

Is there a vaccine for COVID-19? At the time of printing, there are currently 12 potential COVID-19 vaccines in phase-3 clinical trials. Pfizer, Moderna and AstraZeneca-Oxford have been the first to release data. If a vaccine is proven safe and effective, the World Health Organisation (WHO) will work to facilitate fair access for the billions of people who will need it. The best estimates predict a safe and effective vaccine may be ready by mid to early 2021. Some countries have started rolling out programs already.

How is the research process being accelerated without compromising safety? Because of the impact of COVID-19, priority has been given to funding and administrative support, and this has prevented the usual delays. In the past, vaccines could take years to develop, as there are bureaucratic delays such as submitting funding requests, ethics approval, recruitment regulations, funding cuts etc. At present, some research steps are happening in parallel, for example some trials are evaluating multiple vaccines at the same time. However, this does not make the studies any less rigorous.

Will the COVID-19 vaccines be safe? Strict protections are in place to help ensure the vaccines are safe. All products will have passed multiple rigorous testing processes. This includes Phase 3 trials, which involve testing the vaccine on tens of thousands of people to determine vaccine efficacy, and identify side effects. All trial results are public information and are externally regulated by independent research bodies, including the Global Advisory Committee on Vaccine Safety, WHO expert panels, plus officials in individual countries who will decide whether to approve the vaccine for national use.

How effective are COVID-19 vaccines? Early data results are looking promising. Pfizer/BioNTech conducted a Phase 3 trial involving over 43,000 volunteers. Half received the vaccine and half were injected with a placebo of salt water. Over a period of months, 170 trial participants developed COVID-19. Of those, 162 had the placebo compared to only 8 in the vaccine group. As 8 is 5% of 162, Pfizer reports a 95% efficacy rate of stopping people getting sick.

U.S. drug manufacturer Moderna has produced data showing a 94.5% efficacy. In their trial of 30,000 patients, 95 participants developed COVID-19. Of these, 90 had received the placebo and just 1 had been vaccinated. AstraZeneca-Oxford's trial of 20,000 people has shown 70% efficacy after 1 dose and 90% efficacy after 2 doses.

It's important to recognize that vaccine effectiveness in the 'real world' may be slightly lower than the trial results. This is because trial settings are ideal, but 'real world' factors may create obstacles. For example, refrigeration conditions during transport, vaccine delivery technique, and timing of doses may differ slightly from the trial settings. However, >90% trial efficacy is very promising; the U.S. FDA only requires a minimum of >50% trial efficacy to consider approval of a vaccine.

Importantly, these results only show how the vaccine reduces the number of people getting sick (only sick participants were tested for COVID-19).

The trials are not testing whether the vaccine reduces the rate of asymptomatic infections.



A COVID-19 vaccine may be ready soon

Novel coronavirus: *the vaccine*

Do vaccines prevent infection, illness or both? The trial results show whether the vaccine protects people from getting sick, rather than testing if asymptomatic participants were still getting infected with the virus. To test this concept about infection rate, researchers would need to vaccinate trial participants and then deliberately expose them to the virus to see if they get infected. These types of studies are called “human challenge trials” and are usually only performed when a treatment is widely available. At the end of the day, most people want a vaccine that will reduce their chance of falling ill, and the upcoming vaccines appear capable of doing this. If they also reduce the rate of infectivity, then that will be beneficial too.

In terms of reducing the severity of illness, both Pfizer and Moderna show promising results. Of 10 severe cases of COVID-19 in Pfizer’s trial, only one person had been in the vaccine group. Of 11 severe cases in the Moderna trial, none came from the vaccine group.

Until evidence about infectivity rates is available, you should continue to be vigilant about ensuring appropriate social distancing, plus be attentive to hand-washing and face mask hygiene advice. These techniques remain the best way to prevent getting an infection in the first place.

Will the vaccines protect vulnerable people? Moderna and Pfizer have been active at recruiting older individuals and people with comorbidities, to make sure the vaccine will be equally as useful in vulnerable population groups. For example, more than 40% of Pfizer’s trial participants were over the age of 56 years, and 42% were from a non-Caucasian racial or ethnic background. The company’s aim was to ensure the efficacy of its vaccine was consistent “across age, gender, race and ethnicity”.

How long will the immunity last? This question can only be answered after months or years of following the study participants, as part of Phase 4 observational trials. Treatment with rituximab can remove B cell-produced antibodies from the blood, which may make the vaccine’s protective ability short lived. Discuss this with your Doctor, if it applies to you.

Can I have vaccines if I have CAD? Yes and no. Vaccines contain components of either dead or attenuated (weakened) bacteria or viruses.

Because vaccination ‘primes’ the immune system, it can result in an exacerbation of CAD hemolysis. As a general rule, it is recommended that individuals with CAD should not be vaccinated with live vaccines. Examples of live vaccines include those against chickenpox, TB and measles/mumps/rubella (MMR).

While case reports of CAD worsening after vaccination are very rare, it is a good idea to pay attention to your symptoms after vaccination, and to notify your doctor if you suspect that your hemolysis rate is increasing. Important symptoms might include fever, dark urine or excess lethargy.

What type of COVID-19 vaccines are being made? None of the major COVID-19 vaccines are ‘live’. This means they should be safe in CAD, as long as your doctor has approved it-

Moderna: RNA, 2 doses 28 days apart.

Pfizer/BioNTech: RNA, 2 doses 28 days apart.

Oxford/AstraZeneca: Non-replicating viral vector, 2 doses 28 days apart.



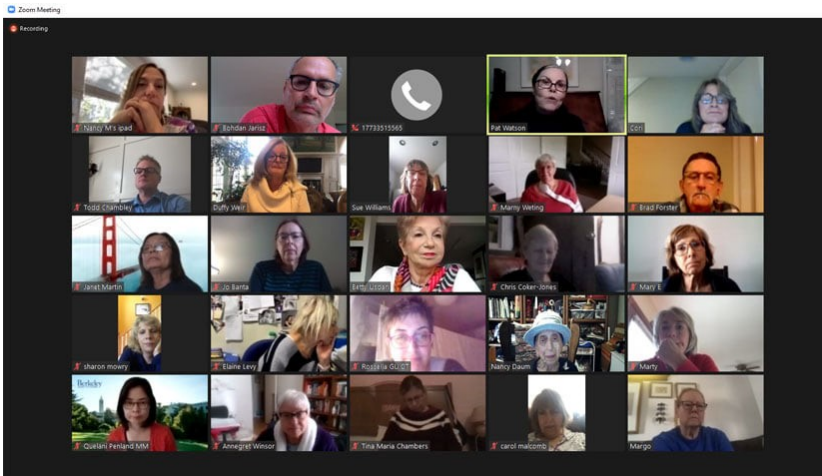
A COVID-19 vaccine may be ready soon

The mRNA technology is not new (its >15 years old), but it hasn’t yet been used widely for mass production, because of the expense of transportation (which requires -70C or -94F temperatures to keep the mRNA stable). While the Moderna and Pfizer vaccines need to be kept cold during transport, they are thawed prior to administration. In any case, because vaccines contain a small volume only, there is no need to worry about their temperature as long as you yourself are keeping warm overall.

For a concise summary from an Expert in CAD, click this link to our CADF website: https://coldagglutininidisease.org/news-release-cad-dec-2020?fbclid=IwAR2ZgS8t2BWBX_TI4HUMdneFAzVgMBvqXzh7o793z9iNE3guizRLG2emFWg

Will the vaccines worsen my CAD?

CADF's first Zoom meeting!



Thank you to all those who organized, or participated, in our first ever Worldwide Zoom meeting on 5th November 2020!! We really enjoyed the opportunity to meet so many of you!

Please head to the private CADdy Chatter Facebook page for the Zoom meeting link, if you missed it. We plan to have more Zoom meetings in the future, including in different time zones, to facilitate more widespread participation. Thank you everyone for your support. [Upcoming dates](#) have been announced on our social media sites!

Infrared camera and Cold Agglutinin Disease at a local museum

Hello, my name is Alison Fendley, I was diagnosed with Cold Agglutinin Disease in 2001. Our family has season passes to a local science museum in our area. One day, while we were enjoying a visit to the museum, we noticed that it had a new infrared camera. If a picture is worth a thousand words, the attached images speak volumes about the impact of Cold Agglutinin Disease on the body.

My husband and I put our hands under the camera and noticed that his hands were all glowing and bright and mine were as dark and lifeless as the photos show. We both looked at each other astonished, and commented to each other that mine must look that way because of my Cold Agglutinin Disease. I snapped a picture, because we thought this gives a perfect visual of the effects of CAD. We also decided to take off our shoes and get an image of our feet. Thank goodness there were not many people at the museum that day- taking off our shoes felt a little awkward, but I really wanted to get a picture of it. It is really hard for a lot of people to even know what you are talking about when you try to explain CAD; this at least gives a little visual to go with the explanation of the disease.



CAD: around The World!



One of the biggest talking points about CAD, is the notion that cold weather can be life threatening for people with this disease. The idea that many individuals have to move to warm or tropical climates in order to live better- it's unparalleled by any other rare diseases. This is something that sets CADdys apart. This unique peculiarity is often hard to explain to others, but tends to get the most attention or fascination. CADF aims to increase awareness of CAD, and spread the word about this unusual disease where you have to avoid cold weather, swimming, ice-creams....

To counter wide-spread travel restrictions, we aim to bring the world to you! Here, CADdys share information about their country, climate and healthcare system experience. Thank you very much to all who participated :)

Being a CADdy in New Zealand- *Mike Hannah*



New Zealand, to many people in other countries, means the All Blacks (our national rugby team), or our stunning mountain scenery, or a small fruit named 'kiwi' after our national bird. We also make a lot of milk, lamb, and wool.

The country enjoys a temperate climate, ranging from the 'winterless north', and some great beaches, to snow-clad mountains in the south. I live mid-way, in the capital, Wellington, one of the windiest cities in the world.

Wellington weather ranges from frosty winter mornings to mid-20s C (about 70F) in summer. And there is that wind chill. So, for a CADdy, it has its challenges in winter. Thankfully, health care has been excellent since my diagnosis in 2019.

Our health care is largely tax-funded primary care (with part-payment by the patient) and free hospital services. If you can afford it, you can also access private specialist services, which can be part-funded by insurance.

I was diagnosed in the private system, after accessing different physicians quickly to explain my falling haemoglobin and haemoglobinuria (hemolysed blood in the urine). After CAD was diagnosed by a haematologist, I went to the public system, where further tests and Rituximab treatment were readily available for free.

The next step would be to hit the cause of my CAD, an indolent lymphoma, with chemo, but my haematologist is waiting a year. Given the challenge that would be to my immune system, that's wise until we have an effective COVID-19 vaccine.

And I can then look forward to enjoying northern hemisphere summers in our winter!



CAD: around The World!

Being a CADdy in England— Frances Firmin

I live in Cornwall, in the West of England. We moved here when we retired in 2011 so we could live in the countryside near the sea, and in peace and quiet. The climate here is quite mild, with little frost in the winter and the summers are pleasant although generally not as hot as in the South East of England.

I was diagnosed with CAD during the course of a routine “new patient” check up and blood test when we registered with our local medical practice after we moved here. We have a largish local general hospital within 15 miles of home and I was initially under the care of the haematology/oncology team, but I intensely disliked the dismissive attitude of the senior consultant and requested to be transferred to a university hospital some 40 miles away- where the team are nothing short of wonderful. They are kind, helpful and empathetic, and over the years I have been under their care I have come to rate them almost as friends.

Medical care here in U.K. is free, as are prescriptions for the over 60s and, while our local medical surgery is significantly overworked and sometimes hard to access, I have the comfort of knowing I have an “open appointment” with the hospital team which requires only that I pick up the telephone if I feel I need to be seen by them.

My life is very “outdoorsy”. I walk our three dogs every day whatever the weather, and the only adjustments I make are in what I wear- which is always much more than anyone else I meet out on my walks! My husband and I are great travellers and, in particular, we have a penchant for the South Atlantic, including the Falkland Islands and South Georgia. We love whales, seals, penguins and all the other sea and bird life to be found in that area. With the right clothes and proper care, we have travelled across from the South of Chile to South Africa twice in the past, and plan to do so again in 2022. We also ski but only in April in Canada, high on the glaciers. For me this is only possible on sunny days for a short time, but it is possible.



Cornwall is renowned for its beautiful beaches, with scattered heritage sites where there was previous tin, copper and arsenic mining. The countryside has gained more fame from the recent BBC series (and novels) titled *Poldark*.

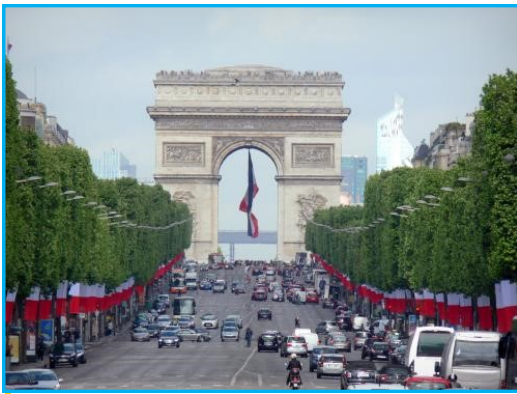


I am grateful to be relatively mildly affected by CAD. I suffer from continuous low level haemolysis, which causes me to experience mild anaemia and consequent lack of energy but I regard myself as very lucky that by taking the right care of myself, keeping warm and maintaining a healthy balanced diet I am able to live a pretty full life. I cannot know how different it might have been had I not developed CAD, as I have never been 71 before!

Cornwall is the origin of Cornish Pasties, famous across the U.K.

CAD: around The World!

Being a CADdy in France—Jane Dougherty



I developed CAD in 1998 (age 38) after my fourth baby when I was living north of Paris, very cold winters and a cold house. I was diagnosed with haemolytic anaemia, sent to a Paris hospital (hospital treatment in France is free) for tests where they did everything including a bone marrow biopsy but found no reason for the haemolysis. I refused to let them remove my spleen, ‘just to see’, and for the next nine years I was treated on and off with cortisone because they didn’t know what else to prescribe. I also had another baby. I was sick, weary to death, and mildly depressed- especially in the winter. Medical opinion was, if you have five kids, you’re bound to be tired.

It was only when we moved south to Bordeaux in 2005 where the weather is very mild, that my haemoglobin started to rise steadily and I started to feel better. In 2010 I had the good luck to be seen by a replacement haematologist at the hospital (I had been followed by the head of haematology) who had written his thesis on CAD. He recognised instantly what the hospital in Paris had missed, and diagnosed CAD. Since I have primary CAD and no other illnesses at all, and because my haemoglobin is stable at around 11g, I have no treatment except folic acid and a dose of vitamin D in the winter.

I have the impression that it’s a disease that few doctors know anything about, and don’t know what to do about it- anyway I’m lucky with the weather and having otherwise good health!



Healthcare systems

around the world



Universal Coverage

(single-payer system)

The government (‘single payer’) covers everyone by a national health care plan

e.g. Cuba

Universal Coverage

(multi-payer system)

Everyone is covered under a national health care system. Competing private options are available to those who can pay.

e.g. France, Germany, Australia, New Zealand, Canada

Multi-payer system

(no universal coverage)

Not everyone is covered.

People have health plan with government programs or private insurers.

e.g. U.S.A

No national health-care

(fully out-of-pocket)

No government options exist. There is limited health care access from individual companies and aid organizations.

e.g. India, Ethiopia, Bangladesh





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

Cold Agglutinin Disease Foundation

E-mail: info@cadfadvocacy.org

Website: <https://coldagglutininidisease.org>

Facebook:

Business page- Cold Agglutinin Disease Foundation
Support group- CADdy Chatter



Complete your online profile at:

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

to receive up to date information about virtual meetings, events, first release of the newsletter, volunteer opportunities, promotions and more!

CADF Quizmaster Challenge!

D O R D S P L E E N H L D I F O N A S N R D F
 L O H D L A T N A S N E V I T A L Y C J E W S
 J K O O B E C A F R X Z M T S P A I N F I Y K
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 S W B R I T U X I M A B Y H S R O T C O D G G

PERSISTENCE

Definition: To persist!

This word is very applicable to 2020! How many words can you find by re-arranging its letters? Write them below:

Find the following words in the puzzle.
Words are hidden ↑ ↓ → ← and ↘ .

- | | | | | |
|--------------|--------------|-------------|-----------|-------------|
| AGGLUTINATE | CLINICAL | HEMOGLOBIN | REINDEER | SPLEEN |
| ANEMIA | DOCTOR | HEMOLYSIS | RITUXIMAB | SUTIMLIMAB |
| AUTOIMMUNE | FACEBOOK | ITALY | SAMPLE | TOES |
| BENDAMUSTINE | FOLATE | LABORATORY | SANOFI | TRANSFUSION |
| BILIRUBIN | FOUNDATION | LDH | SANTA | TRIAL |
| BLUE | FRANCE | MITTENS | SCARVES | USA |
| CADDY | GERMANY | NEW ZEALAND | SKIING | WARM |
| CADF | HEMATOLOGIST | PERIPHERY | SPAIN | ZOOM |

5 words: Try harder!
 10 words: Well done :)
 12 words: Impressive!
 >15 words: QUIZMASTER!!!!
 Congratulations on your perseverance!