



Lupus News

Tasmania

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Committed to understanding and supporting people with Lupus, Sjogren's,
Schleroderma & Fibromyalgia or any autoimmune disease



CROHN'S DISEASE

Office Bearers

Lupus Association of Tasmania Inc.
Registered Charity ABN 96 163 951 956

All Correspondence to:

PO Box 639
Launceston 7250
Tasmania Australia

Ph. 0407 327 780

Email: lupustas1@lupustasmania.org.au

Website: www.lupustasmania.org.au

Patron: Hon. Michael Ferguson MP

President: Dr. Lois Beckwith

Vice-President: Karen Madge

Secretary/Public Officer: Dianne Whiteley

Treasurer: Murray Scales

Committee: Cheryl Dent, John Dent and Helen Edwards

East Coast Co-Ordinator: Jasmine Rooney

Email: jasmine.rooney90@gmail.com

Phone: 0401543175

Northern Coordinator: Lois Beckwith

E-mail loisbeckwith@bigpond.com

Phone: 6369 5393

North-West Coordinator: Charmaine Smigielski

E-mail: silvicharms@gmail.com

Phone: 0419 422 076

Southern Coordinator: Heather Cowled

E-mail: lhcowled@bigpond.net.au

Phone 6272 3096

West Coast Coordinator: Barbara Gruner

E-mail: barbara.rosalie@yahoo.com

Phone: 6471 6506

Editor: Dianne Whiteley

E-mail: lupustas1@lupustasmania.org.au

Librarian: Madi Lowe

Phone: 0490 120 611

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We would like to acknowledge the Hon Mr. Michael Ferguson MP and his staff for the printing of our Newsletter and his continued support. **Congrats** on being re-elected 😊

The Lupus Association of Tasmania, Inc. does not recommend or endorse any drugs, treatments or procedures reported in this newsletter. The information is intended to keep you informed and we recommend that you discuss any information mentioned with your Doctor.

From the Editor's Desk

Crikey! The year is disappearing quickly. May 2021 already and so much happening regarding Lupus Association of Tasmania Inc.'s members.

We held our AGM in March. Fantastic day! Firstly, to the members who stood down, **THANK YOU** so much for all the help and support you gave to the committee. We appreciate you 😊

To the new committee members...**WELCOME ABOARD** 😊. To the members who continue to be on the committee, we are truly **THANKFUL** to you as well. The association has been running for around thirty years so let us 'keep on keeping on'!!

Committee is:

President: Lois Beckwith

Vice President: Karen Madge

Treasurer: Murray Scales

Secretary: Dianne Whiteley

Members:

Justin Churchill

Cheryl Dent

John Dent

Helen Edwards

Madi Lowe

Colleen McCormack

We also **WELCOME** Madi Lowe 😊 She was elected at our AGM to be our new Librarian (as well as on the committee!!!

We also **WELCOME** Charmaine Smigielski as the new north west support coordinator but say farewell to Leanne Collins who has been at the helm for a long time. **THANK** you so much for all your dedication and time you gave to your role. We wish you all the best with your future.



President Lois and NWSGC Charmaine

President's Message

News from President Lois

For the 2021 year I decided to set a variety of new personal targets for myself, to make up for what I missed last year. So, I am now on a journey of ticking off each challenge I have set.

My first challenge was the 3 Capes Walk. It was a lovely walk, full of steps and ups and downs, far too many to count. It is world class and the accommodation and guides with the Wilderness Company was exceptional. The odd glass of wine and a deep massage on day 3 were all deeply appreciated and considered an essential of life. The last days walk was the toughest especially for me as the pack did not get any lighter and I was three times older than the guide. Hauling the c-pap machine and my 26 different medications certainly helped fill my pack.

My second challenge is the Overland Track, but I am having trouble getting a booking in the next season. It seems it is now on every walkers 'must do' list.

My third challenge is a 5-day Trek in the Flinders Rangers for the Australian heart Challenge. This is a fundraiser for the Heart Foundation. My normal routine is 2 hours with Zara (my dog) the feral one around Deloraine with the Heart Foundation each week. I am to raise \$3,000 for the cause; any ideas on how to achieve this?

Not a bad effort for an oldie living with chronic lupus. The more I do the better I feel. I hope all our members have set a challenge that they can work on for the year.

Best regards...from the highly insured walker.

Lois



Three Capes Walk – 48km



Overland Track -65km



6-day Flinders Ranges walk (one walk – 17km)

NOTE: If you have any ideas re fundraising or would like to help, please phone Lois on 6369 5393 and leave a message..... she will be out walking lol

Regional Reports

Northern Support Group

Our group commenced with a cafe meeting at Peckish in Kings Meadow. The staff really thought we were a strange group, some had breakfast, some had morning tea, while others had an early lunch.

We were all happy to meet up again and we have welcomed two new members Karen Madge and Jan McKay. We look forward to involving you more during the year. We were going to go on a café adventure but we like this café so much we will be having our meetings from now on here 😊 We are aiming to have a Christmas in July combined meeting with the north west support group...keep an eye out on our Facebook page and website for more information.

Lois Beckwith
Northern Coordinator

North West Support Group

The North West group will continue to meet at the Fuchsia Farm but on the last Mondays of the month. I have been very busy with life including a catch up with our president Lois. It was a nice afternoon. I have also been catching up with our members. I am looking forward to meeting all our wonderful members as well as new members at my first official luncheon as the NWSG coordinator at Fuschia Farm Café on the 31st of May 2021.

Charmaine Smigielski
North West Coordinator

Southern Support Group

The Southern group met on the 17th of May 2021 and enjoyed the time together. Even though the number of members attending is low due to illness and other commitments, we enjoy the conversation and each other's company. The other meetings for the year are August 16th and November 15th, 2021, Covid19 cooperating 😊.

Heather Cowled
Southern Coordinator

West Coast Support Group

Even though it has been cold, and we have had some crazy weather, it is always great to catch up with members at our meetings. Yes, we have had lots of news to share!! Come along and see what we are up to at the next meeting. 😊

Barbara Gruner
West Coast Coordinator

*** From the LAT committee and members from each support group, we pass on our deepest sympathy / condolences to those who have lost loved ones this year xx

Our thoughts and love go out to you all.





If I Could Catch a Rainbow

If I could catch a rainbow
I would do it just for you
And share with you its beauty
On the days you're feeling blue

If I could build a mountain
You call your very own
A place to find serenity
A place to be alone

If I could take your troubles
I would toss them in the sea
But all these things I'm finding
Are Impossible for me

I cannot build a mountain
Or catch a rainbow fair
But let me be what I know best
A friend that's always there

Helen Steiner Rice

KIRSTY'S STORY.....

My name is Kirsty, and I live in Tasmania – I have recently turned 30 and was diagnosed with Crohn's Disease when I was 21.

Looking back, it was such a stressful, frantic, and harrowing time for me. As with most things I do, my body did not present in standard "textbook" manifestation, meaning the diagnosis period was arduous, expensive, and frightening.

I had a lot of neurological pain type symptoms, as well as a general fatigue that no nap could ever quench. I was told I might have MS, a brain tumour, myasthenia gravis, porphyria, nothing - "it was all in my head", lupus, and the list goes on. I had all sorts of scans and tests done repeatedly before an autoimmune marker in my blood was elevated.

I actually felt relieved that finally something had shown up- I was feeling full of hopelessness and had resigned to the fact that I was probably crazy. Despite finding out I had an autoimmune condition; I was feeling validated and vindicated.

The next step was finding out which autoimmune condition I had - this was challenging as I had a vast array of symptoms - generalised pain, loss of nervous function, nausea, arthritis-like pain, vomiting, some diarrhoea, irritated eyes, constant ear and tonsil infections, weak muscles, anxious, depressed, trouble sleeping, nightmares, oral allergies to raw fruit and vegetables (that came out of nowhere), fatigued, lack of sensation in my extremities, weak, no appetite. The list goes on....I completed my first of many stool samples since - and straight away my faecal calprotectin was elevated. This test measures inflammation in the gut, they talk about 50 being a significant enough elevation to being symptomatic and in an active state of disease, my score was over 1000. I then had a colonoscopy (first of many) which confirmed that diagnosis.

At the time my bowels were functioning pretty normally. I had a gut that was sensitive to dairy & FODMAPs, but never imagined that to be the organ that was trying to kill me. I remember telling a colleague and her telling me that she knew someone with Crohn's who passed away at age 37, and that I probably would too.

I entered the world of relying on medications shortly after- steroids, Imuran, tramadol, etc. My body decided that on top of having a condition that is attacking itself constantly, it would be highly sensitive to most medications I took orally. I recall projectile vomiting at my former workplace while serving people at the cash register, I vomited more than at the beginning of my diagnosis than I had ever in my whole life. I had many strange reactions including completely dismayed pupils for a couple of days, not being able to feel my body and the emergency responders thinking I was on Ice, to collapsing in the shower from sheer weakness. It was a crazy time and often felt that the medication was making me feel worse than if I had not taken anything at all.

To this day I have not had a complete diagnosis that I feel truly explains all of the symptoms my body exists, and due to this I have felt a resentment and lack of faith in my medical team. I live with chronic and largely unexplained pain that all doctors I have seen shun and placate. This has led to me feeling like I cannot properly share what is happening with my body as I felt that no one really wanted to help me. I only take issues to the doctor when I am positive there is a serious issue, and this delaying of medical treatment has probably resulted in further damage to my body that could've been avoided. Additionally, when I do bring up issues with my doctors, I am always very tentative and reluctant which comes across as me downplaying my symptoms and doctors not knowing the full circle. Such a vicious cycle.

The craziest treatment I had was a Faecal Microbial Transplant, where I got my now ex-partner to syringe frozen vials of donor's stool matter up my bum for 10 days. It is not a suggested treatment for Crohn's and has little evidence or research, however I was desperate to live a normal life so decided to give it a crack (lol). It was uncomfortable, gross, frightening but provided me with 2 good years where I was feeling the best I had in a long time. At this point, I had begun the unfortunate journey of being administered with immune suppressing drugs, as all oral medications had proved fruitless. I was on Infliximab for a few years and found it a really confronting experience- it was probably the first time I could not deny that I was unwell. I really do not enjoy needles and found the constant cannulisation highly distressing.

I was feeling that this medication did not truly hide all of my symptoms and my gut symptoms were getting worse- nausea, vomiting, diarrhoea, reflux, etc, and insisted that I change medications. My doctors believed that I was being dramatic and that it was just a sensitive gut. Eventually I changed to the self-injectable medication called Humira. This remains one of the most traumatising experiences of my life, the Humira injections were painful. So painful that it felt as if a knife was stabbing me. I screamed, cried, ran away, became suicidal, in order to not have to deliver this fortnightly torture. My boyfriend at the time was very supportive and had to inject me at home, by laying across my body so I could not run or push him away and inject me despite my anguish.



I have never known time to go so fast- two-week increments passed so quickly. I told my doctors about this and they were unsympathetic to how this drug was causing me distress. I had nurses inject me and try different methods to avoid pain but to no avail. I hated this medicine and hated my body for putting me through it. Eventually my medication was changed to Stelara, which I still currently take. I don't feel this this drug is truly containing my disease, but with limited options I will have to keep taking it.

In 2019 my health declined, I remember telling both of my doctors that I was feeling worse, that I had new and worsening symptoms. I was told I was depressed, anxious, too fat and that I was being dramatic. Towards the end of 2019 I convinced my specialist to send me for a MRE scan. I was called up as soon as he received the results and met with a very confused doctor. Apparently, I had fistulas (holes in intestine), strictures (narrowing of intestine), ulcers (infections, bleeding) in the terminal ileum area of my gut. I had undergone regular colonoscopies and reported all of my symptoms and was brushed off and made to feel like I was stupid. I am still so angry at my medical team for ignoring my cries for help. I was booked in for a right hemicolectomy, where the infected parts of the intestine are removed. I was very lucky and only had 25cm removed. I was really anxious about waking up and finding out I had a stoma (external "bum" formed with intestines that exit via your tummy and a bag is attached that collects waste). I had terrible pain in hospital, only to be remedied by the incredible drug, fentanyl.

It seems funny to me now that a stoma was what I was most scared of, now I am left with ugly scars over my abdomen that ache and repulse me, and with a mess of intestines that have never recovered. I have lost a lot of control over my intestines, causing me to go long periods without eating so I did not have to deal with living my life out on a toilet. I take a packet of Imodium every few days so that I can eat enough to survive, but that only helps to control the gut side of things. My generalised pain, neurological symptoms, fatigue, and mental health symptoms have never recovered, and I imagine never will.

This brings us to recent times, my health continues to decline, I have given up talking to my doctors as I do not feel that they care greatly about my health. I have lost 30 kg in a couple of months, and completely lost my appetite. I was told that if I lost weight everything would be fixed- turns out that's wrong. Despite having many physical, physiological, and mental struggles, I hate to burden those around me with the constant updates of my ill-health to only receive frustrating advice and poorly thought-out responses.

It has only been the last few years that I speak about it with a modicum of transparency- and I have been inspired by the beautiful children that I teach. I would hate for them to ever experience the feelings of abandonment, loss, and hopelessness that I have felt through-out my journey. I like to be open with them about how I'm feeling- to ensure they do not need to feel like they need to lie and play off how they are feeling. I believe it is important for kids to learn about all sorts of lives and stories, as it helps to create more empathetic and thoughtful people- I have been proven correct on this front by the amazing kids that I have been teaching. We have fostered a true culture of safety, openness, and trust so that we can all be our authentic selves.

My students have been inspired by Thrive and JCP Empowering Youth to create positive changes in the world around them. I encouraged my students to challenge themselves to create change in someone's 'world' and felt hypocritical not to create my own. My students have raised money for sufferers of the Beirut Explosion, for war veterans, the community garden, and have bolstered the community together to thank them, to clean up our town, and to spread love and happiness- all their own ideas and planning. I decided to challenge myself to run (i was not a healthy or fit person) 38 laps of our school oval to symbolise the 37 years my former colleague predicted I'd live to, plus one more. So, 38 laps of a 400m oval, meaning 15.2 km. My training began and was arduous due to a

sore body, and a car crash I was in prior to Christmas. Lots of people told me I would never run this distance, that no one would want to run with me, that I would not raise any money or help anyone. I am very stubborn and competitive, so this only drove me further. I trained for hours in heat, rain, darkness to ensure I could put my best foot forward. I created an event and invited the community to join me, asking for any donations to go towards research in a cure for Crohn's disease.

With a broken & battered body, but a determined and motivated spirit I somehow ran my 38 laps a few days before I turned 30. Not only did I run them, I ran them with over 60 people supporting me on my running track. Plus, more who were sitting trackside cheering us on. Friends, students, school families, my family, and people I had never met before. It was the most amazing day, and I could not have completed my challenge without these people present. Not only have I managed to raise over \$1000 on the day, over \$3000 in online donations, and I pledged to donate \$1/lap that everyone completed which came to 1038 laps- or 1000 more than I did, which is just incredible. So, I will have raised over \$5000 when I deposit my personal donation, which I am flabbergasted by.

I have recently joined the local women's football team and was deeply moved when I turned up to training (late) one day to see my team running 38 laps for me. I was so surprised, and this and everyone's support has really touched me. I have been so emotional & overwhelmed due to the kindness and generosity exhibited. People have really surprised me and been so generous with their money and time. I am so thankful to everyone who has donated and supported me through this. To my friends for helping me organise everything and for going above & beyond, my colleagues at school for helping so much, the school P&F, the local football ground for letting me use the club rooms, my local football team for their generosity, and my beautiful students who helped me train at school - without them I would not have achieved this. They are so inspiring and will absolutely be changing the whole world for the better as they all grow older. I am so lucky to teach in a small yet connected community who gather together to support outsiders like me. I know that my students are in safe & supportive hands as they continue to grow & develop into tomorrow's future.

I decided to keep momentum and plan to complete a marathon in November, raising money for disadvantaged and at-risk youths which is a passion of mine. The cause will help push me when times get tough.

Thank you so much for reading my story. I wish you all the best with your own health. Look after each other, trust your gut, be kind to everyone, and be kind to yourself.

Kirsty Holmberg
(North West Support Group Member)



**** If you would like to share your story (anonymously if you wish), please send an email to: lupustas1@lupustasmania.org.au**

Crohn's Disease:

[Crohn's Disease](#) is a condition that causes inflammation of the digestive system (also known as the gastrointestinal tract or gut). Inflammation is the body's reaction to injury or irritation, and can cause redness, swelling and pain. Crohn's Disease is one of the two main forms of Inflammatory Bowel Disease (IBD). The other main form of IBD is a condition known as [Ulcerative Colitis](#). Crohn's is sometimes described as a chronic condition. This means that it is ongoing and life-long, although you may have periods of good health (remission) as well as times when symptoms are more active (relapses or flare-ups). In many people the disease runs a benign course with few flare-ups, while other people may have more severe disease. Crohn's Disease is not infectious.

At present there is no cure for Crohn's, but drugs, and sometimes surgery, can give long periods of relief from symptoms.

Causes:

Although there has been much research, we still do not know exactly what causes Crohn's Disease. However major advances have been made over the past few years, particularly in genetics.

Researchers now believe that Crohn's is caused by a combination of factors:

Viruses, bacteria, diet, smoking, certain medications, and stress have all been suggested as environmental triggers, but there is no definite evidence that any one of these is the cause of Crohn's.

Symptoms:

Crohn's Disease symptoms may range from mild to severe and will vary from person to person. They may also change over time, with periods of good health when you have few or no symptoms (remission), alternating with times when your symptoms are more active (relapses or 'flare-ups'). Crohn's is a very individual condition, and some people may remain well for a long time, even for many years, while others may have more frequent flare-ups.

Your symptoms may also vary depending on where in your gut you have Crohn's. However, the most common symptoms during a flare-up are:

- Abdominal pain and diarrhoea. Sometimes mucus, pus or blood is mixed with the diarrhoea.
- Tiredness and fatigue. This can be due to the illness itself, from the weight loss associated with flare-ups or surgery, from anaemia (see below) or to a lack of sleep if you have to keep getting up in the night with pain or diarrhoea.
- Feeling generally unwell. Some people may have a raised temperature and feel feverish.
- Mouth ulcers
- Loss of appetite and weight loss. Weight loss can also be due to the body not absorbing nutrients from the food you eat because of the inflammation in the gut.
- Anaemia (a reduced level of red blood cells). You are more likely to develop anaemia if you are losing blood, are not eating much, or your body is not fully absorbing the nutrients from the food you do eat. Anaemia can make you feel very tired.

Diagnosed By:

If you develop diarrhoea, abdominal pain, and weight loss lasting for several weeks or longer, or have blood in your stools, your doctor may suspect that you have Crohn's, particularly if you are a young adult or have a family history of IBD. You'll then need a combination of tests and physical examinations to confirm a diagnosis.

Treatment:

Treatment for [Crohn's Disease](#) and [Ulcerative Colitis](#) depends on how severe the symptoms are, and how much of the gut is affected. There are many different treatments available to help you live well with your Crohn's or Colitis. Together with your IBD team, you can decide what treatment is right for you. At first, medicines aim to reduce inflammation in the gut to bring about remission.

Remission is when you feel better and your Crohn's or Colitis symptoms aren't bothering you. Once

the condition is under control, your doctor will usually continue to prescribe drugs to maintain remission and prevent relapse (feeling unwell again) – this is called maintenance treatment.

Reference: Crohn's & Colitis Australia. 2021. www.crohnsandcolitis.com.au

For more information: www.crohnsandcolitis.com.au / www.crohnsandcolitis.org.uk

MAY 10 – WORLD LUPUS DAY

"My lupus led me to have a kidney transplant last year, but this has not stopped me from being a dad to my beautiful daughter".

LUPUS UK

WORLD LUPUS DAY - 10TH MAY

WORLD Lupus Day

- Lupus is a serious life-debilitating fatal disease where the immune system attacks its tissues and organs
- Every year, May 10th is dedicated to World Lupus Day to fight against this unpredictable & commonly misunderstood disease
- Globally, lupus affects 40-100 people in every 100,000
- The World Lupus Federation invites everyone to provide an in-depth understanding of lupus and support the affected ones so that they are diagnosed and treated effectively

The UK and other countries celebrated WLD on the 10th of May 2021. In Tasmania, we do not celebrate World Lupus Day. We put all our heart and sole into Lupus Awareness Month and celebrate at that time as well. In 2019, we had a walk at Bicheno to raise awareness and funds. THANKS to our East Coast Support Group Coordinator, Jasmine for organising the event. We conduct a raffle and other events as well. Please view page 12 for more details.

For Your Diary



CHRISTMAS IN JULY

The north and northwest support groups are joining forces and conducting a 'Christmas in July' luncheon for all members on 22nd July 2021. Venue to be confirmed!

Note it in your diary and further information will be sent out soon 😊

The regional support group meeting dates are as follows:

East Coast Support Group: In lockdown until further notice 😊

Northern Support Group:

The fourth Thursday of every month at the Pekish Café, 114 Hobart Road, Kings Meadow starting at 10.30 am.

North West Support Group:

Last Monday of every month at Fuschia Farm Café, Lillico Road, Lillico starting at 12pm. Pay for your meal. Please come along and have a chitchat with our other members for an hour or so....

Southern Support Group:

We meet at Mather's House, 108 Bathurst Street, Hobart starting at 12pm. Dates are -**August 16th** and **November 15th**, 2021.

West Coast Support Group:

1st Tuesday of every month at JJ's Café, 13 Orr Street, Queenstown starting at 11.30am. Please come and join us for a cuppa and something to eat.

General Meetings:

All meetings are held at the Launceston Community Health Centre - Joan Marshall Wing, 22 McHugh Street, Kings Meadows. Starting at 11am with shared lunch afterwards. All members welcomed ☺

GM - 13th June 2021

GM - 12th September 2021

GM / Christmas Lunch - 12.12.2021

LUPUS AWARENESS WEEK 18-24th October 2021

Please take note of our LAW date as we will be holding events during that week that we would like members and the public to attend ☺ We will also send out a raffle book to all our members (unless committee have been notified). If you would like to donate a prize, please contact us via email or inbox us on our Face book page.

Prizes donated / the winners from 2019 were:

- 1st Prize – Landscape Painting donated by Lupus Tasmania Member – Jasmine Rooney
Winner – Helen Whittle - East Coast Support Group
- 2nd Prize – Accommodation at Engadine Cottage, Mole Creek donated by Lyn Stedman
Winner – Lance and Heather Cowled - Southern Support Group
- 3rd Prize – Family Pass into Trowana Wildlife Park donated by Androo Kelly from TWP
Winner – Kate Alderidge - Southern Support Group
- 4th Prize – Tasmanian Truffles Gift Pack donated by Henry Terry from TT
Winner – Edna Brock - Northern Support Group
- 5th Prize – Pampering Gift Set donated by Prospect Pharmacy
Winner – Megan Lucas - East Coast Support Group
- 6th Prize – Gift voucher from NewBed Hairdressers (Railton) and Prospect Hairdresser
Winner – Pat Flowers - North West Support Group
- 7th Prize – Wine and Chocolates - Winner – Michael Griggs - Southern Support Group