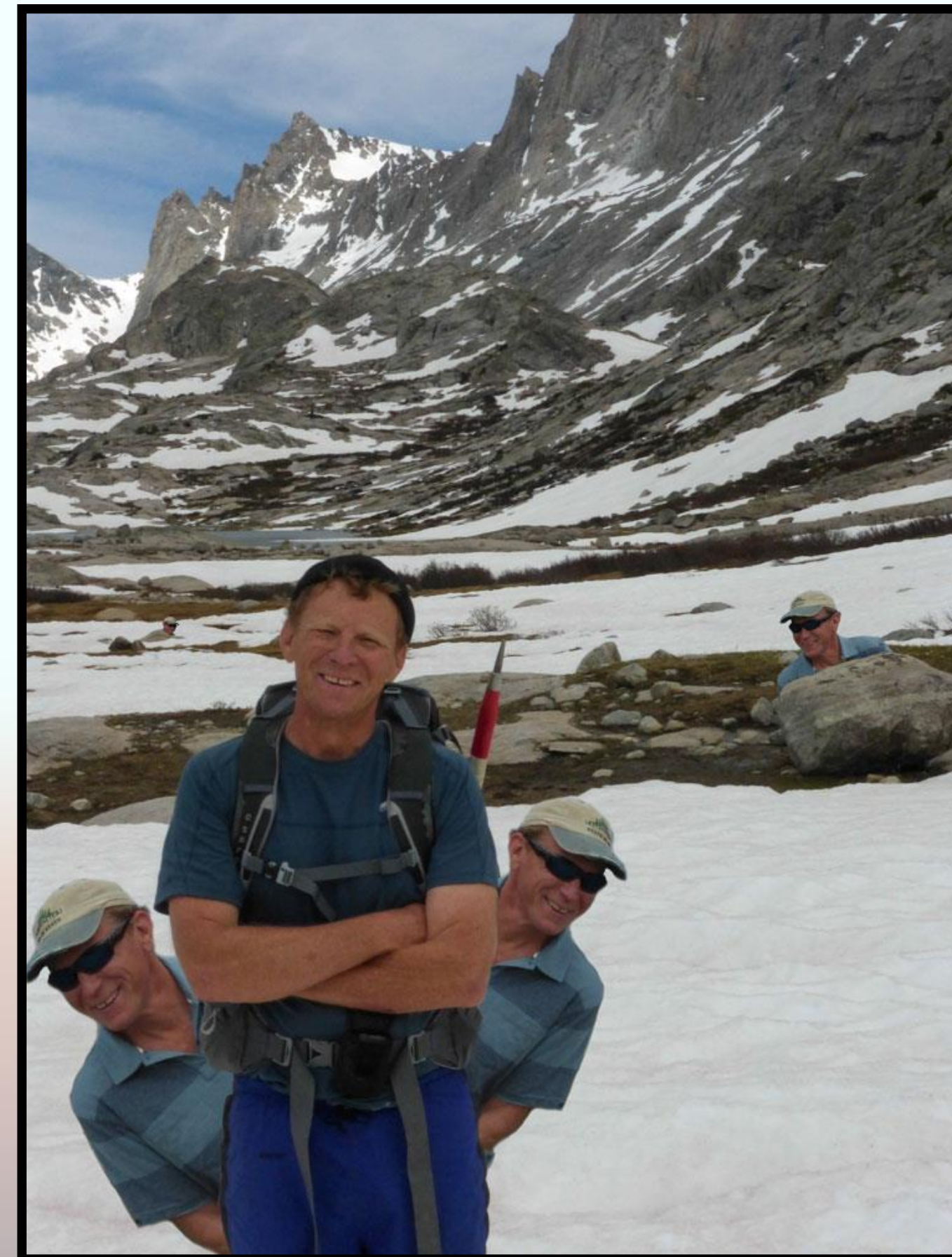


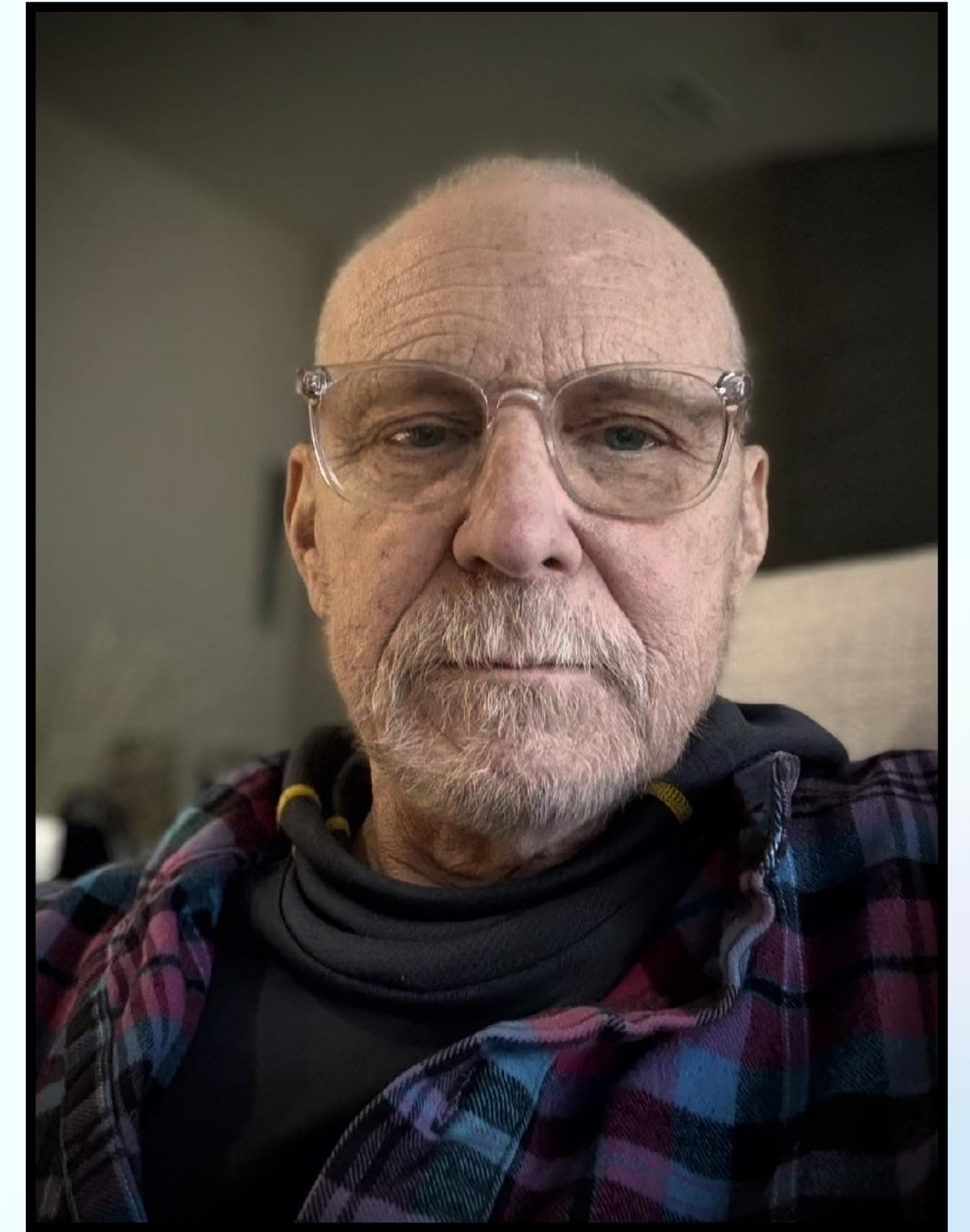
Let's Focus on Exercise and Its Importance Regarding Chronic Graft Versus Host Disease Post Transplant

Matt Willen, Patient
Jeffersonville, VT



Who is Matt Willen?

- I live in Jeffersonville, VT. Very far northern Vermont
- 67 years old
- I have two grown sons, Ian (24) and Jackson (27)
- Work at Stowe Mountain Resort in Base Operations (10th year this year)
- Used to be a college professor in Pennsylvania (1997-2016); specialization was writing and literature of travel and exploration
- Lived in the southwest (CO, UT, NM, AZ) where I worked in outdoor programs such as for the Colorado Outward Bound School (Late 1970s until mid-1990s)



Exercise and Me

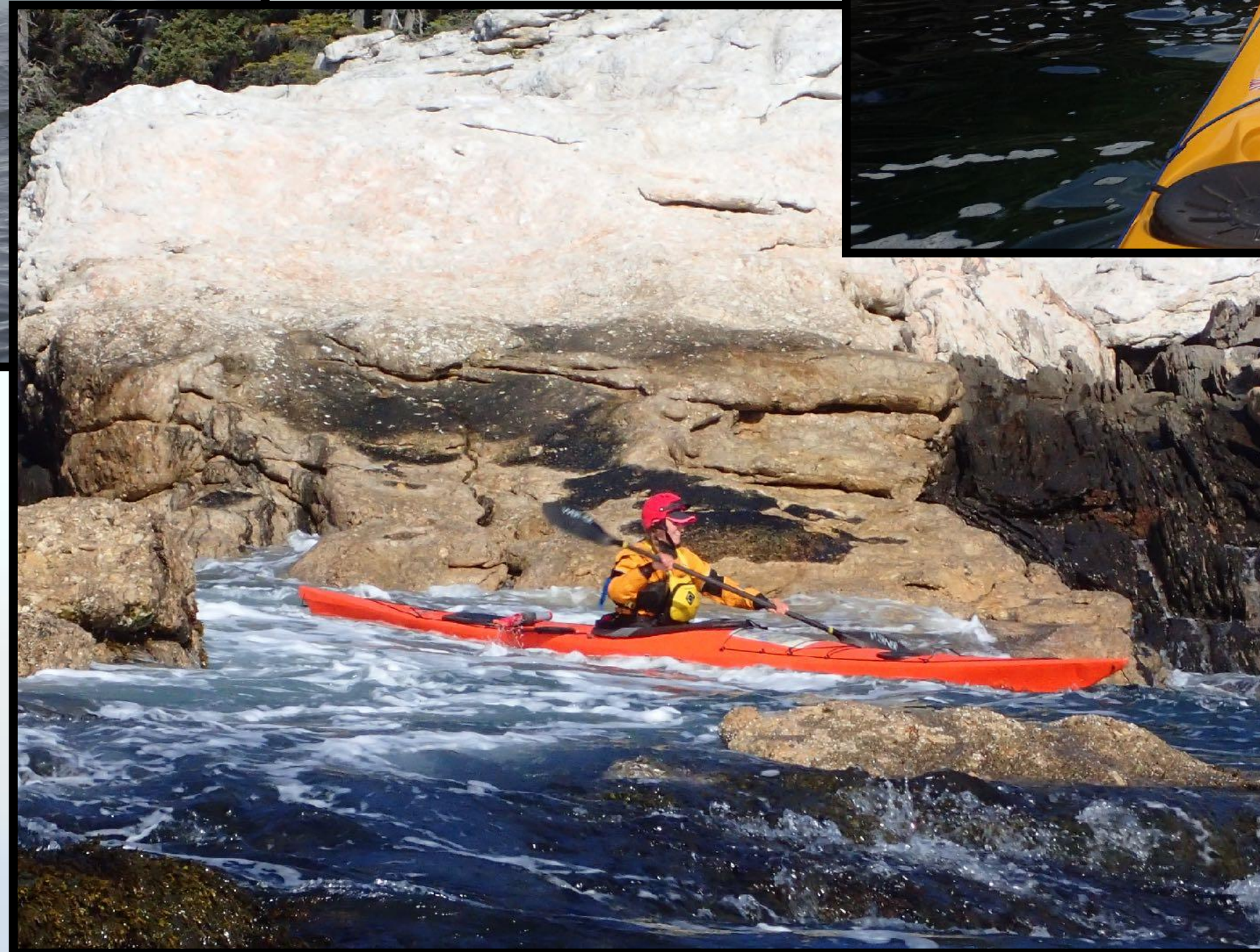
- I'm not a person who "exercises;" that is, you would almost never hear me say, "I need to go out and "exercise."
- Why? I get exercise by being me, doing the things that I do that are intrinsic to who I am and how I see myself
- What are those things?



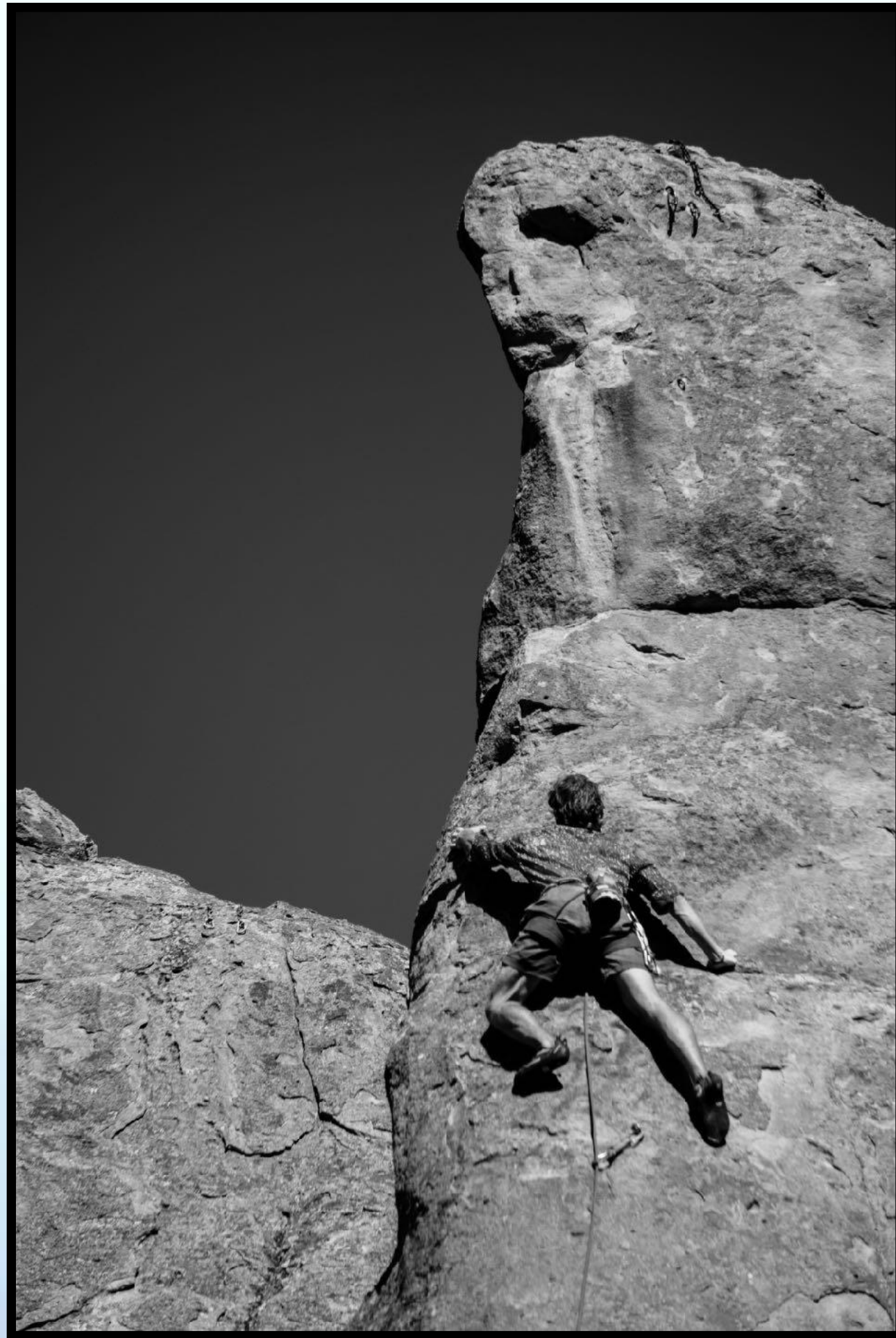
Work at a ski resort, so I am a skier



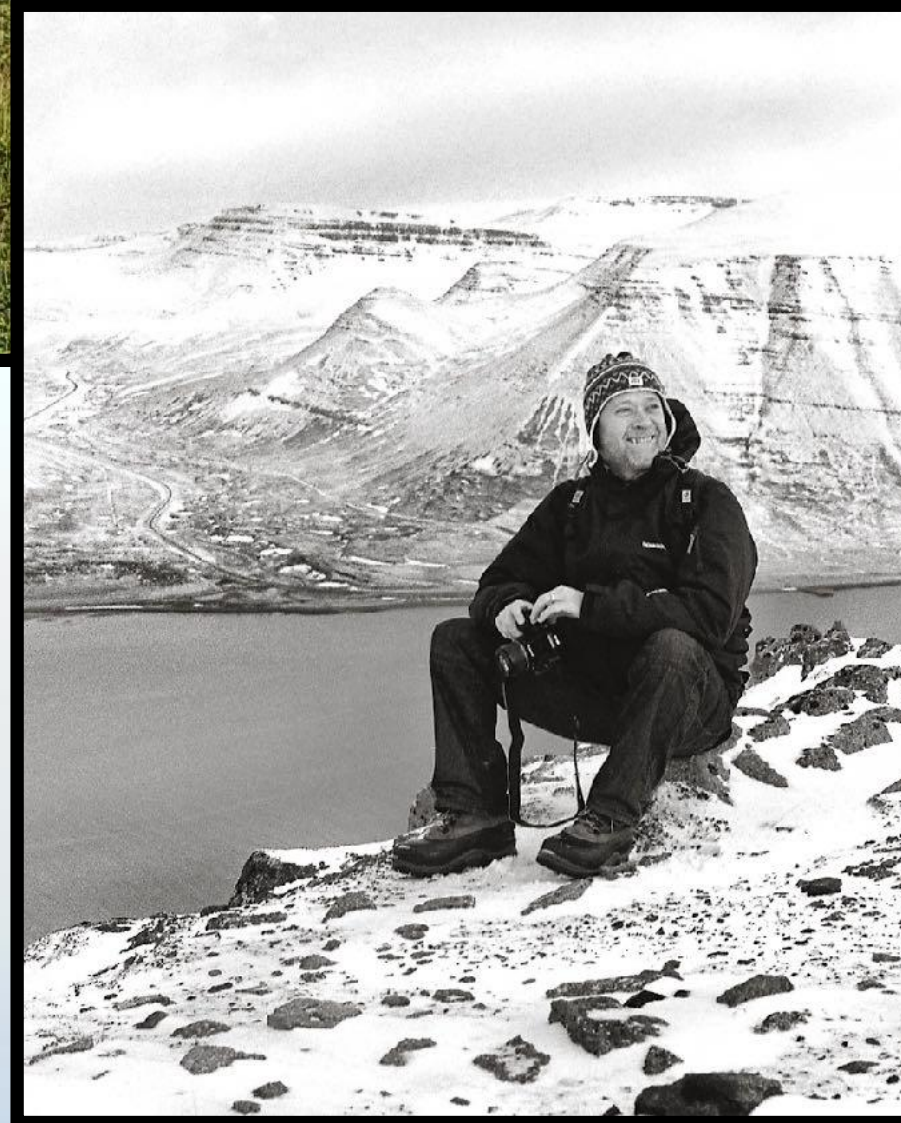
Sea kayaker



Rock Climber and Mountaineer

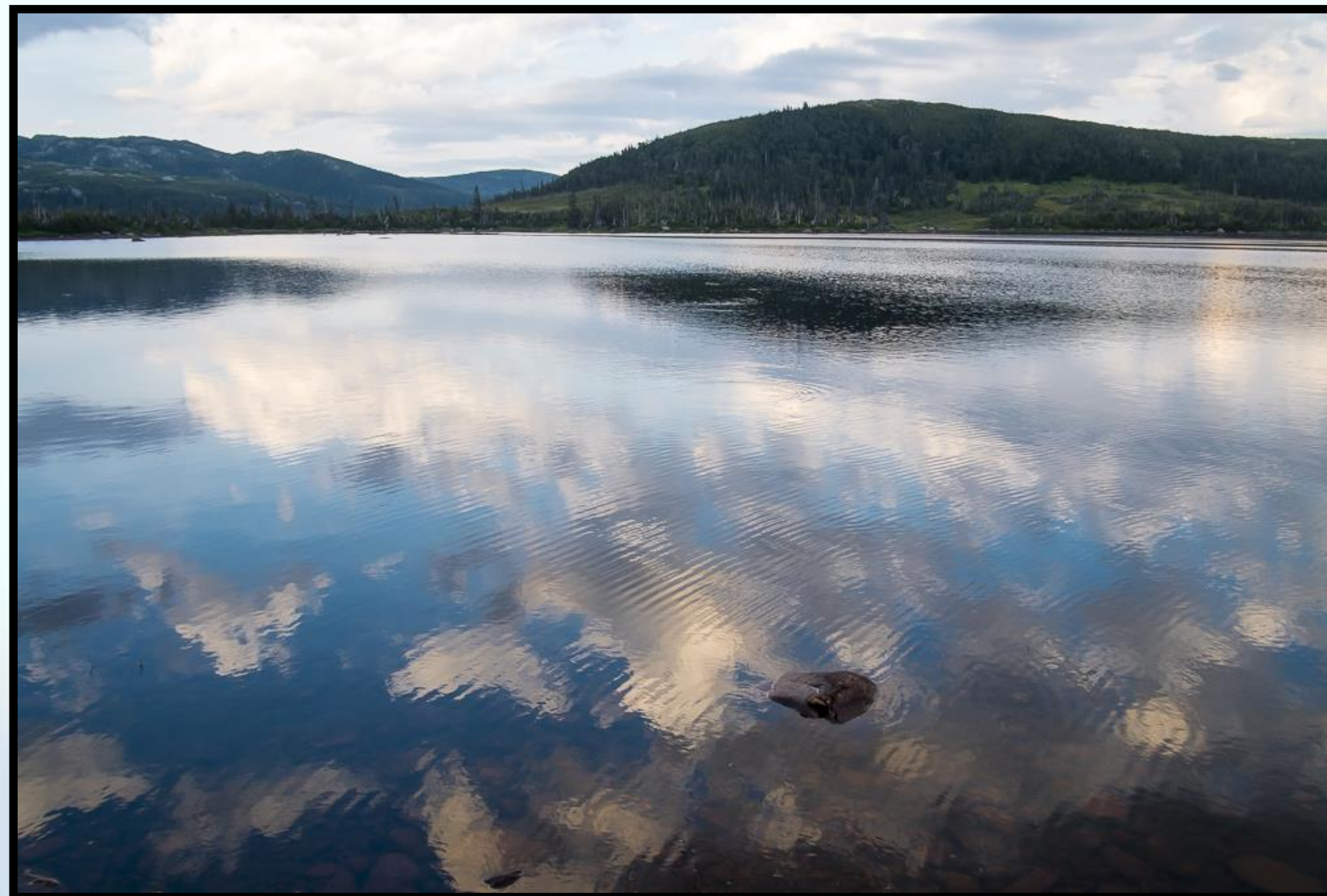


Adventure Traveler



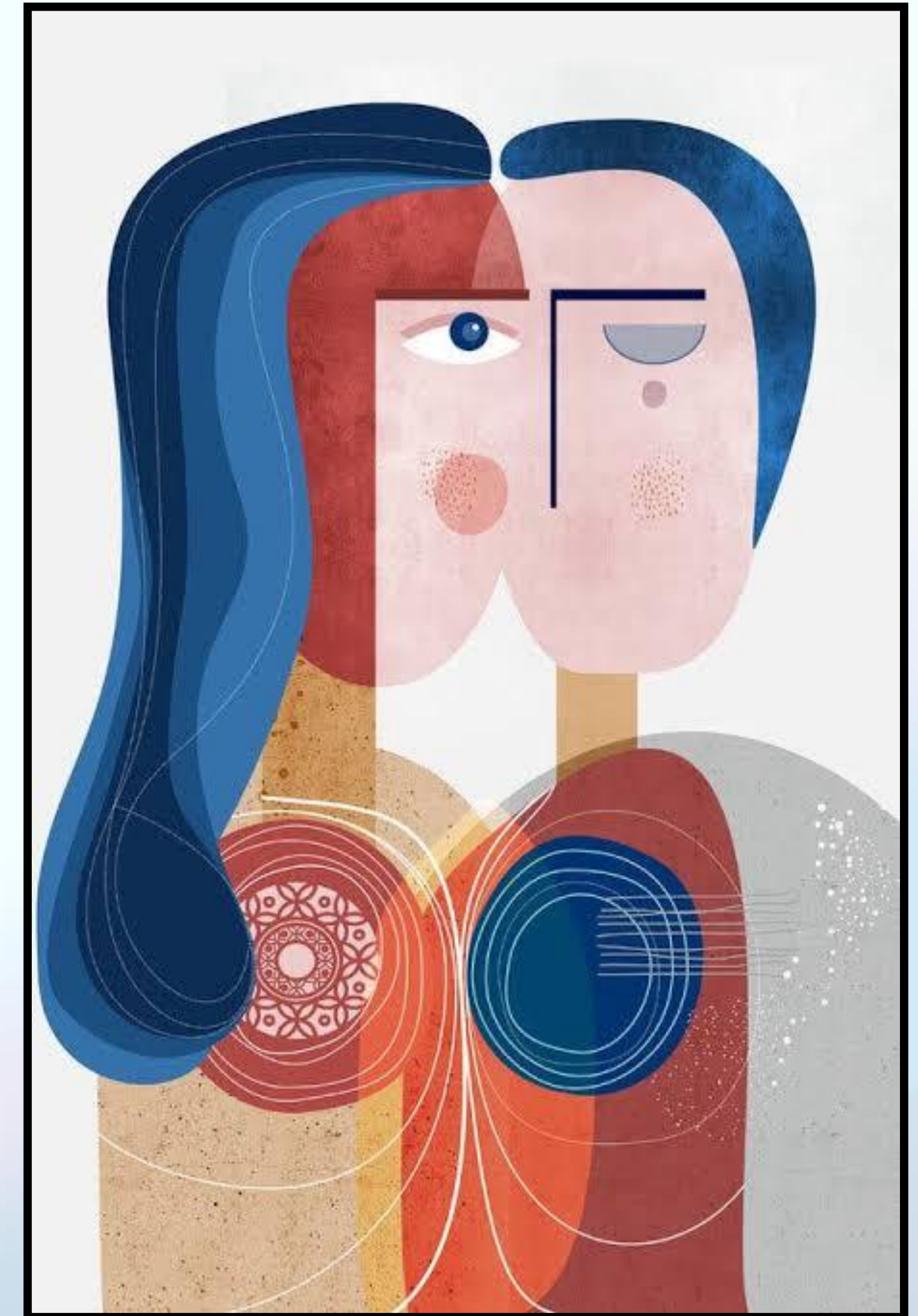
Exercise and Me

- Each situation presents its own unique set of challenges
- “Exercise” for me is about keeping myself in shape *and* allowing me to be who I am. And that sense of “who I am” is something that really gets challenged when going through a stem cell transplant.



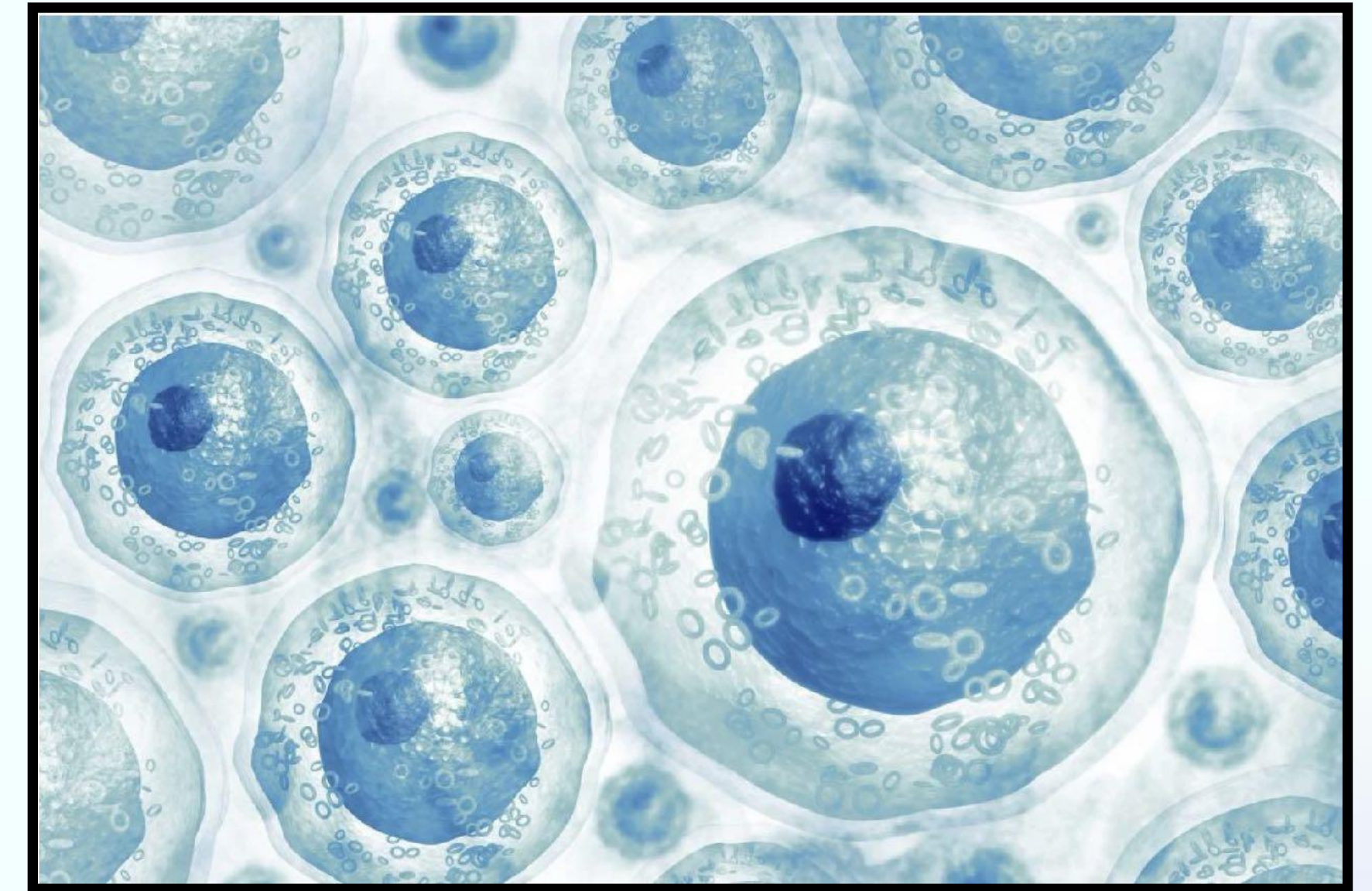
My Clinical Story

- Hairy Cell Leukemia (2002 and 2011)
Treated with chemotherapy both times
- Chronic Lymphocytic Leukemia (2021) with del 17 and TP53 mutation
Treated 2022-2023 with Venetoclax and Gazyva (obintuzimab)
Treated 2023-2025 with Calquence (acalabrutinib)
- Richter's Transformation —> Diffuse Large B Cell Lymphoma (5/2025)
Treated with R-CHOP + Venetoclax (5/2025-9/2025)
Stem Cell Transplant (10/15/2025), some minor acute GvHD
- Relapse (1/2026)
Treated by stopping all immunosuppressants (2/2026)
Near immediate remission



My Chronic GvHD

- Onset after stopping immunosuppressants and has persisted
- 3 primary issues
 - Dryness of the mouth
Treating with cevimeline to enhance saliva production
 - Dryness of eyes (wake-up-in-the-middle-of-the-night gritty eyes and photosensitivity)
See an ophthalmologist; punctual plugs in all my tear ducts; steroidal eye drops (prednisolone); preservative free over-the-counter eye drops; PF eyelid wipes
 - Overall photosensitivity
Lost tolerance for being out in the sun and for warm (over 75 degrees) weather



Exercise and Stem Cell Transplant

- Even before transplant, while on R-CHOP, I was out hiking in the woods around my house to keep myself fit and to keep myself sane. Some days I could go 3 miles, some days 1/2 mile. It was important to be out. It was something I could do when everything was being done to me.



Plan and Adapt

- Learned that in order to exercise with life after Stem Cell Transplant generally and cGvHD issues specifically, I have to PLAN ahead and ADAPT my routine. I can't be as spontaneous as I was.
- Started planning for life post-transplant even before I had it. Lived in Boston for three months post-transplant; so I considered how I could get out without having to drive.
- Rented a condominium on Jamaica Pond and the Emerald Necklace (c. 8 miles greenway) which allowed me to be outside and walk everyday.



cGvHD of the Mouth When Exercising

- Dealing with lack of saliva production and dry mouth is easiest to address BUT has real consequences for dental issues and mouth sores

- PLANNING: What I take with me

- Always pack a thermos of lemonade or tea in the winter (drink more than water). Pack sugar free gum. Pack dried fruit for <1 hour.

- ADAPTING: I chew gum a lot; I stop for drinks a lot; I don't let myself dry out. Try to breathe through my nose. In the winter I wear a face mask (helps keep my mouth moist) and limit my time out.



cGvHD of the Eyes When Exercising

- Pretty challenging; I have to keep moist all the time
- PLANNING ahead before I go by gathering what I need; “My eye kit” which I store in a pouch
 - PF eye drops; wrap around sunglasses; goggles in the winter (keeps the wind out of my eyes); eyelid wipes (around my eyes gets very goopy and need to be cleaned); glasses cleaner
- ADAPTING my routine
 - Stop a lot to take care of my eyes, before I “need” to;
 - No rubbing eyes;
 - Wearing close fitting eye protection all the time;
 - Try not to go out in the wind;
 - No driving after dark, which is also planning related



Photosensitivity and Exercising

- Also very challenging; sun has become the kryptonite to my superman; doctor explains it as a type of cGvHD and can cause other kinds of cGvHD
- ADAPT: LIVE LIKE A BAT (doctor's orders!)
Go out at dawn and dusk;
Stay in the cool of my house mid-day;
Eat insects; Take frequent breaks;
Pray for clouds (VT is very cloudy);
Realize there are things I can't do
- PLANNING:
When will I go out?
How will I shape a trip?
Wearing sunglasses, sunscreen and SPF clothing



Exercise and cGvHD: PLAN and ADAPT

- In summary, PLAN and ADAPT are the two things that I need to do in order to continue to be Matt with cGvHD
- Every situation is different and needs to be thought out in advance
 - Kayak trip to Quebec late September
What do I need to do in order to be safe and comfortable?
 - Future trips to the desert or the high mountains
How will I manage the sun?
Need to see what future summers hold in store
- Thank you and please feel free to contact me
exploromat@gmail.com

